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Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e111>

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Children's Representations of Asthma: Developmental Changes and
Influences on Knowledge, Asthma Control, Management
and Perceptions of Quality of Life.

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Submitted in partial fulfilment for the requirements for the degree of
DOCTORATE OF CLINICAL PSYCHOLOGY

CLINICAL PSYCHOLOGY
SALOMONS CENTRE
ACCREDITED INSTITUTE OF THE OPEN UNIVERSITY

SEPTEMBER 1996

Date of award: 11th September 1996

ACKNOWLEDGEMENTS

I would like to thank all the children and their parents who gave their time to participate in this research and to the GP's for their interest and co-operation. Particular thanks go to my supervisor John Weinman and to Margie Callanan for their support and to Graham Dunn for statistical advice. Thanks also to my proof readers Antoinne Schembri Wismayer and Carmen Magri. Finally a big thank you to my family who, through their support and patience, made it possible for me to absent myself from the world.

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DEVELOPMENTAL CHANGES AND THE INFLUENCE AND KNOWLEDGE,
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ABSTRACT

A between and within group design using a semi-structured interview was used to explore the content of children's illness representations of their asthma and the influence of these representations on knowledge, asthma management, asthma control and perceived quality of life. A sample of 41 asthmatic children and their parents were recruited from GP practices. Children were divided into two age groups 8-11 years and 12-16 years. Test-retest reliability was performed on a sample from each age group. Children were found to have similar illness representations across the age groups although developmental patterns were found in the beliefs children offered about the cause of their asthma, and in the way in which illness representations influenced outcome. For the younger children, causal attributions appear to be more influential in outcome than the constellation of illness representations that were tested. Older children appeared to be beginning to approximate more adult patterns of holding a set of beliefs that influenced outcome. A major issue in the study was the variable reliability of the measures used. Stability over time for the younger children was attributed to greater parental influence. The instability of measures over time for older children was considered to reflect developmental influences. Some support was found for the proposed self-regulatory function of illness representations although the complexity of findings highlights the need for longitudinal research to track developmental changes in children's illness representations. The implications for future research and clinical practice are discussed.

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1. INTRODUCTION

Asthma represents the most common childhood illness (Eiser,1993). Greater awareness and modern advances in medical treatment should mean that control of symptoms is within the grasp of all but the most severe and intractable cases. Yet from research findings it is clear that many children continue to experience symptoms which can significantly compromise the quality of their lives (Eiser & Havermans, 1994). The impact on children's lives has been considered in terms of impact on daily living and the psychological consequences to childhood asthma. There appears to be enormous variation in children's response to asthma and in their ability and willingness to manage their condition. Previous research has considered the role of the family in managing asthma. Although considered important, little is known about how the child perceives their asthma. This study will concern itself with a child-centred approach to childhood asthma and focus on how the child's understanding and perception of their illness may influence management and the impact that asthma has on daily life.

This introduction will consider first the nature of asthma, its prevalence and treatment. Second the impact of asthma on life at home and school and the child's psychological well-being. Third the role of self-management and work that has attempted to teach children how to manage their illness. The final section will integrate some of the psychological factors that influence the child's ability to manage their illness.

1.1 The Nature of Asthma.

Asthma is an aetiologically complex disease the main symptoms of which are coughing, wheezing and breathlessness (Hilton, 1994). An almost universal feature of asthma is airway hyperresponsiveness to a variety of stimuli, including allergens, non-specific irritants and infections (Pearson, 1991). Symptoms arise as the result of variable airway obstruction due to constriction and inflammation of the airways in response to these “trigger factors”, giving rise to the characteristic wheeze and breathlessness (Hilton, 1994). Attacks occur on an intermittent basis, are variable and may reverse spontaneously or as a result of medication, they may also vary independently both between patients and, over time, within the same patient (Creer, Stein, Rappaport & Lewis, 1992).

The aetiology of childhood asthma is not precisely known (Pearson, 1991). Diagnosis is based on clinical presentation which may vary enormously from mild episodic asthma which occurs when the child is exposed to high loads of allergens or on exertion, with emotional arousal or in conjunction with respiratory tract infections to severe chronic asthma which is responsible for considerable limitations of activities (Price, 1994). Acute attacks can occur with all these different presentations although they tend to occur more frequently in the most severely affected children (Hilton, 1994). Although it had been considered that most children will “grow out” of their asthma, recent research suggests that less than half of asthmatic children become and

remain symptom free in adulthood and about 30 per cent who do “outgrow” asthma in adolescence have some recurrence in early adult life (Gerritsen, 1989)

1.1.2. Prevalence

Asthma is the most common of all childhood chronic illnesses, community prevalence is estimated at a rate of eleven per cent for diagnosed childhood asthma (Price, 1994). Although there have been increases in the diagnosis of asthma, which would affect prevalence rates, there appears to have been an increase in the prevalence of more severe childhood asthma over the past 10-20 years (Speight, Lee and Hey, 1983). With this has been an increase in hospital admissions which have doubled in school-age children and quadrupled in pre-school children (Price, 1994). Death rates have fluctuated but have not shown any decline, and about forty children die of asthma each year, mortality being highest between the ages of 10-15 years (Price, 1994).

1.1.3. Treatment

In all but the very mildest of asthma treatment consists of two aspects. Firstly reversal of the bronchoconstriction with inhaled bronchodilator drugs. These drugs, which act on the smooth muscle in the airways, have an immediate effect. Secondly prophylactic medication is given to suppress the underlying inflammatory response in the airways by

means of inhaled or, in severe episodes, systemic corticosteroids (Upchurch and McCulloch, 1994).

1.2. The Impact of Childhood Asthma

1.2.1. Impact on daily living

Asthma accounts for the greatest number of school absences with more school days lost because of asthma than any other single chronic illness in childhood (Wells, 1994). Some studies report high levels of academic underfunctioning as a result (Rachelesfsky, 1986). The restrictions and limitations for some children can impact physical and social participation. Schlosser and Havermans (1992) found that in a group of adolescents with asthma 33 per cent reported that they participated less in age appropriate activities such as dancing and going to pubs. Eiser, Town & Tripp (1989) suggested that of her sample of asthmatic children 85 per cent were affected by exercise- induced asthma, with 65 per cent of children limiting their activities to help to avoid attacks. Conversely Weston, Macfarlane, & Hopkins (1989) , Routon and Sherril (1989) found little evidence of differences in activity levels or enjoyment, which would suggest that some children adapt their lifestyle to their limitations with greater ease than others.

1.2.2. Psychological impact

Asthma is a distressing illness and studies have sought to identify the nature of distress felt by children. Usherwood, Srimgeour and Barber (1990) identified that respiratory symptoms were rated as the most distressing and burdensome with many children reporting feelings of frustration, fear and anger when experiencing these symptoms. Similarly Eiser et al. (1989) found that children unanimously gave very negative accounts of their asthma which included fear about dying, inability to take part in certain activities or to have pets. The social impact was frequently expressed in negative terms and children reported being and teased by others and embarrassed when they made wheezing noises, or needed to use inhalers in public.

The findings of work in this area suggests that for some children asthma can seriously compromise their psychological well-being. This effect appears to be unrelated to disease severity (Perrin, MacLean & Perrin, 1989). Mrazek, Anderson and Strunk (1985) found a significantly higher level of psychological disturbance among children with asthma than among controls. Similarly Kashani, Konig, Shepperd, Wilfley and Morris (1988) found a greater number of anxiety and phobic symptoms in asthmatic children aged 7-16 compared to children seen for acute non life-threatening illness. Other work has explored factors that may contribute to fatality among children with asthma and Mrazek et al (1985) found that children whose asthma proved to be fatal had been more depressed and shown greater family dysfunction than those with non-

fatal asthma. Similarly Fritz, Rubenstein & Lewiston (1985) found depressive symptoms and denial of illness as identified mortality markers for children with asthma. It is not clear however, to what extent depressive or anxiety symptoms are caused by asthma or whether depression and anxiety inhibits a child's ability to control their symptoms. Control of asthma symptoms, however, appears to be an important factor and Staudenmayer (1982), Norrish, Tooley & Godfrey (1977) and Kashani et al (1988) suggest that psychopathology is higher in children who have poor control over their asthma which is unrelated to severity.

Other research has not found significant differences between children with asthma and healthy controls on measures of psychological adjustment such as self-esteem or self-concept (Kashani et al, 1988, Ostrov & Ostrov 1986). On measures of psychological health Norrish, Tooley and Godfrey (1977) found no differences in emotional difficulties between asthmatic children and the general population and Perrin et al, (1989) found overall psychological adjustment was comparable with that of healthy children. Creer et al (1992) suggest there may be positive outcomes with children who are coping well and gain a sense of mastery and control over their symptoms. As with other chronic diseases, there appears to be enormous variability in the way in which children respond to asthma. It is not clear, however, what mediates adjustment.

1.2.3. Methodological Criticism

There may be a number of possible explanations for the mixed findings in term of psychological health; firstly that measures used vary and make comparisons between studies difficult. Some authors have used disease specific measures whilst others have used more global measures of well- being or psychopathology. Global measures are problematic because other risk factors in a child's life may influence these results other than illness related distress. Global measures of distress, that include symptoms which may be a direct result from the condition or treatment, may also lead to an over-estimation of the degree and incidence of emotional distress.

Secondly, there is no standard definition of what is meant by mild, moderate or severe asthma and the way severity is assigned varies between research. Some work has used prescribed medication to assign participants to severity groups. This is problematic because different criteria are used to determine severity. The Norrish et al (1977) classification is often used, whereby the severe group would include children who are prescribed any form of inhaled corticosteroid. Other studies use the dose of such inhaled steroids as a measure of severity. Thus many of the children classified as severe will represent a wide range of children using variable amounts of inhaled corticosteroid maintenance therapy. Other work has used measures of pulmonary function, which may be confounding severity with control

1.2.4. Problems of measuring impact

The mixed results may also reflect that the impact of asthma on the child is complex and difficult to measure. There may be a number of reasons for this, firstly that attempts to assess impact often use other's perceptions rather than the child's. Research suggests that accounts from parents, doctors and children often differ. Kashani et al (1988) found that asthmatic children were viewed as having greater psychopathology by their parents than their doctors. Christie, French, Sowden & West (1993) found that although children's perceived severity was significantly correlated to the doctors ratings, distress was not. Thus a doctor may be a poor judge of his patient's distress from asthma. It is possible that the distress and burden experienced by a child may not be adequately assessed by others.

The second issues relates to how outcome is defined. Objective measures such as physical data of lung function or medication use have been used as indices of effective outcome. Although objective measures are clearly informative, Weinman (1994) suggests that it is often assumed that objective measures are more real than the patients' perceptions. This was demonstrated by Christie et al (1993) who found that although objective measures of lung function were related to children's physical restriction, they were not related to the child's perception of severity or distress about asthma. Hyland, Finnis & Irvine (1994) would suggest that subjective evaluations can be as or more predictive than purely objective measures of health status. This was

demonstrated by Staudenmayer (1982) who found that children's attitudes about the quality of their life with asthma were significantly correlated with the number of attacks, hospitalisations, casualty attendance, number of days lost from school and interference with physical activities.

French & Christie (1995) suggest that a measure of children's quality of life needs to incorporate both objective indices and subjective measures of burden and distress. A child-centred approach to measuring quality of life with asthma has been developed by Christie, French, Weatherstone and West (1991). The measures include various aspects of a child's life such as the amount and enjoyment of age appropriate active and passive activities and the child's perceptions of severity and distress. In a sample of 127 children with mild asthma, subjective severity and distress about asthma were considered to be psychologically distinct for children and independent predictors of active quality of life. The mean scores obtained from a larger sample of 242 children found that moderate to severe asthma significantly reduces the quality of daily life although scores from those with mild asthma do not differ significantly from those of non-asthmatic children. Christie et al (1995) demonstrated that although the quality of daily living shows clear relationships to objective lung function much of the variance in scores was considered not to be attributable to the presence or absence of symptoms. Thus it would seem that subjective quality of life is more closely related to how children feel than to how symptomatic they are.

A major difficulty in assessing children's perceptions has been the consideration that children may not be reliable informants (Rosenbaum, Cadman & Kirpalani, 1990). Reliability of a measurement over time is more problematic in children because their own abilities and attitudes may be changing rapidly due to normal developmental processes. The accuracy of children's self reports will also depend on their cognitive ability to understand concepts being measured and the required responses must fall within the cognitive capabilities of the child (Christie et al, 1991).

1.3. SELF-MANAGEMENT AND INTERVENTION

Despite the relative effectiveness of medical treatments, many children with asthma continue to achieve less than optimum control and experience unpleasant and frightening symptoms and attacks unnecessarily (Eiser et al, 1994).

1.3.1. Adherence

Non-adherence to medical treatment is postulated as an explanation for why asthma continues to impact on children's lives (Lemannek, 1991). Rates of non-adherence vary with studies reporting rates of between 17 to 90 per cent in children and adolescents (Baum & Creer, 1986). Hilton (1991) reported that in a sample of adolescents only 27 per cent were taking their preventative treatment and 12 per cent were taking no medication at all. Few relationships have been found between

adherence and demographic factors, severity, and duration (Smith, Seale , Ley, Shaw & Bracs, 1986, Weinstein and Cuskey,1985). However, older children may be more non-adherent (Christiaanse, Lavigne & Lerner, 1989). When medication such as bronchodilators are required on a “when needed” basis there are reported difficulties such as over-use, under-use and arbitrary use (Lemanek, 1990).

1.3.2. Self-management

The failure of improved medications to reduce the morbidity associated with asthma has given impetus to a range of interventions focused on patient education and self-management (Hilton, 1994). The emphasis on knowledge is based on the premise that children do not know enough about their asthma or how to manage it. There is some support for this notion in work by Eiser et al (1989), who found that in a sample of children aged 7-16 years many had little awareness about the precipitants of attacks or knowledge about what they would need to do to avoid attacks.

Other research has sought to clarify what it is that children need to know and do to manage their asthma successfully. Creer et al (1992), and Mc Nabb, Wilson- Pessano & Jacobs (1986) suggest that the main requirements for effective self-management are first; the ability to predict and prevent attacks by compliance with medication and avoidance of known triggers. Second to intervene to prevent ongoing attacks from increasing in severity. Behaviours necessary for intervention and prediction include

the use of self monitoring with peak flow meters and behavioural strategies to manage an attack such as, relaxation, medication use, and the ability to seek help on a timely basis when self- management efforts have not been effective. In addition Mc Nabb et al (1985) have identified behaviours that reflect the need for children to manage the social aspects of asthma such as dealing with peers.

1.3.3. Self-Management programmes.

Self-management programmes have been developed using these ideas and aim to educate children in the basic principles of asthma and to help children develop appropriate behavioural strategies to recognise, prevent and control their symptoms. Evaluations of the effectiveness of these programs have produced equivocal results. Parcel, Nader & Tiernan (1980) used a school based education approach and found that improved asthma related knowledge increased perception of control over health, and decreased anxiety associated with illness. Other work however suggests that increased knowledge does not always lead to improved asthma management. Hilton, Sibbald, Anderson & Freeling (1986) found that children who received asthma education had a greater understanding of asthma than those who did not. However, there were no differences in self-management ability by asthma morbidity or age group. The relationship between knowledge and self-management behaviour was explored by Rubin, Bauman and Lauby (1989) who found that as knowledge

increased above a certain threshold there was little change in reported management behaviours.

Other work has looked specifically at the effects of teaching behavioural self-management. Creer et al (1992) suggest that an important factor in self-management is the need to recognise and interpret symptoms. Studies have found that asthmatic children and adults are not able to accurately monitor the state of their airways when unaided by measuring devices (Sly, Landau & Weymouth, 1985). Creer, Backial, Burns, Leung, Marion, Miklich, Morrill, Taplin and Ullman (1988), found that children who are taught to monitor their symptoms and to then respond with a variety of management behaviours show improvement in asthma control. These ideas were incorporated in a large-scale behavioural intervention by Creer et al (1988). Improvements were noted across multiple domains; reduction in attacks, improved prediction using peak flow meters, improved management of attacks, and a lessening of consequences (such as a reduction in school days lost). Creer et al (1988) also noted that there was a dramatic shift in childrens' and parents' attitudes toward asthma as well as enhanced self-esteem.

1.3.4. Problems with evaluation of self-management programmes.

Self-management programmes have directed themselves towards education and the findings of the research reviewed suggest that the relationship between knowledge and

successful self-management is not straightforward. Behavioural methods have shown promising results. However, as programmes tend to be based on multi-components and include education, behavioural strategies and symptom recognition, it remains unclear what components are responsible for change or indeed what changes. The difficulty in assessing self-management appears to mirror the complexities of assessing impact. There would seem to be other important factors that act as barriers to effective self-management that are not addressed in such programmes.

The fact that contemporary treatment of asthma increasingly involves children in the management of their asthma, would suggest that children's perceptions are an important source of information to parents and health care professionals (Christie, French, Weatherstone & West, 1991). It is possible that the beliefs a child has about their asthma may have a moderating effect on a child's willingness and ability to engage in appropriate self-management and make use of such interventions. Yet little is known about how children cognitively represent their illness.

1.4. Psychological factors influencing self-management

Childhood asthma occurs within familial and social network and these will have an influence on children's self-management and outcome. This study, however, is focused on a child-centred approach and as such will concentrate on individual factors that

may influence self-management. These include developmental factors such as the child's understanding of illness generally, and asthma specifically and how a child constructs their illness cognitively. Whilst it is not assumed that these factors develop in isolation other considerations are beyond the scope of this study

1.4.1. Children's understanding of illness

Work on developmental aspects of children's understanding of health and illness, based on the work of Piaget (1929), suggests that children's concepts of illness progress through a systematic and predictable sequence of developmental stages paralleling the pre-conceptual, concrete and formal operational stages of cognitive development (Bibace & Walsh, 1981). Children of different ages, therefore, understand the cause and consequence of illness differently. Perrin & Gerrity (1981) found that young children were likely to assume illness was the outcome of wrong doing and thus the outcome of their own behaviour. Brewster (1982) found that the bulk of a sample of 7-10 year olds believed all illnesses were caused by germs and that the individual bore no responsibility for becoming ill. A consistent finding is that with increasing age and cognitive maturity, children are more likely to conceptualise illness in more complex ways particularly by mentioning specific symptoms, the role of infection or germs and psychological and social factors such as personal actions that can prevent illness: older children are also less likely to use immanent justice and magical explanations for illness (Burbach and Peterson, 1986).

This approach has been criticised for being too narrow and fails to capture the role of social context and individual differences in children's understanding and experience of illness (Eiser, 1989). Subsequent work considers that children are more aware and have greater insight in all domains compared to those originally described by Piaget. Carey (1985) proposes a functionalist account and suggests that the young child's conceptualisation is not constrained at a structural level. Carey (1985) suggests that children develop schematic representations of illness that change in light of increased biological knowledge and understanding of human behaviour. This account would suggest that the fact that children give different explanations depending on age would be based on children's limited experience.

Much of this work has been based on healthy children's concepts of illness; less work has considered or compared the concepts of ill children. It may be expected that children who are ill would be better informed about illness generally and their own illness specifically due to greater personal experience (Bibace and Walsh, 1981). Nagera (1987) however suggests that the stress associated with chronic illness retards cognitive understanding of these concepts. There is support for Nagera's position from a number of studies that have investigated ill children's understanding of their illness (Eiser, 1989, Eiser, Patterson & Tripp, 1984 and Berry, Hayford, Ross, Pachman and Lavigne (1993), all of whom suggest that ill children have less understanding compared to healthy children and it would seem they lack the appropriate knowledge and self care skills about their specific disease (Eiser et al,

1989). In research by Berry et al (1991) conceptions of illness by children aged 7-17 years with Juvenile Rheumatoid Arthritis were explored. They found a substantial number of older children and adolescents, who may be expected to demonstrate a more sophisticated understanding of various aspects of disease, were offering explanations of their illness at a much earlier developmental level. The authors were struck by the within subject variability, inaccuracies and misconceptions that occurred among their sample, most of whom were long time clinic attendees and had been exposed to clinic educational programmes.

1.4.2. Children's understanding of asthma

Martin, Landau & Phelan (1982) found a substantial lack of knowledge in a sample of young adults who had been asthmatic since early childhood. Eiser et al (1989) investigated children aged between 7-17 years on their understanding of asthma and found that over half of children were unable to offer any account of the causes of asthma. Children who did offer an account most frequently cited hereditary factors at 24.5 per cent, allergies were mentioned by 10 per cent of children and 4.1 per cent offered physiological explanations, such as lungs not working properly. Some 10 per cent of children offered a combination of causes. There were no age differences in children's explanations. Eiser et al (1989) found that the majority of children expected to outgrow the condition, and only 16 per cent of children expected to have asthma all

their lives. Age did not influence children's beliefs about when or if they would outgrow the condition.

Eiser et al (1988) have outlined how potentially low children's understanding of asthma is and suggest that this may contribute to continued symptomatology in many children. This view is implicit in the educative focus within self-management programmes. However as discussed the mediating role of knowledge in self-management is not straightforward. There remain uncertainties and complexities in understanding how children perceive health and illness and how they regulate their behaviour accordingly (Weinman, 1994). The next section will draw together the findings of work with adults that has specifically addressed the links between knowledge, perception, symptoms and behaviour.

1.4.3. Illness Representations

There is growing interest in the way individuals perceive or construct mental representations of their illness. Leventhal, Diefenbach & Leventhal (1992) propose that, as a result of personal experience, family and social beliefs people create their own representations of their illness in order to regulate their illness behaviour. These representations are created along a number of dimensions: a set of symptoms with a label, a series of beliefs about the cause of the illness, a set of consequences associated with the illness, and ideas about how long the illness will last. Lau & Hartman (1983)

have added a fifth dimension relating to individual beliefs about control or cure of the illness. Although the components are distinct, and can have specific effects on outcome, they are not necessarily independent and direct links between such elements as representations of cause and control and illness identity and consequences are noted (Weinman, Petrie, Moss-Morris & Horne, 1995)

Leventhal et al (1992) suggests that an individual's illness representations forms an underlying cognitive structure that organises and processes illness information (Fig.1). Within this structure is a concrete somatic level and an abstract level of formal knowledge about various illness. Thus some of the self referent illness perceptions an individual holds will be close to conventional medical or widely known knowledge about particular illnesses, some will be more divergent and idiosyncratic. Such divergent perceptions are noted in the beliefs younger children hold about illness that changes with development such as illness being related to magic or immanent justice.

These illness representations are the individual's way of making sense of the various threats and demands of illness and change with disease progression, emergent symptoms and treatment response. Illness representations are considered to be guides to action and directly influence behaviours associated with management, such as adherence and coping and via this with outcomes such as mood and disability.

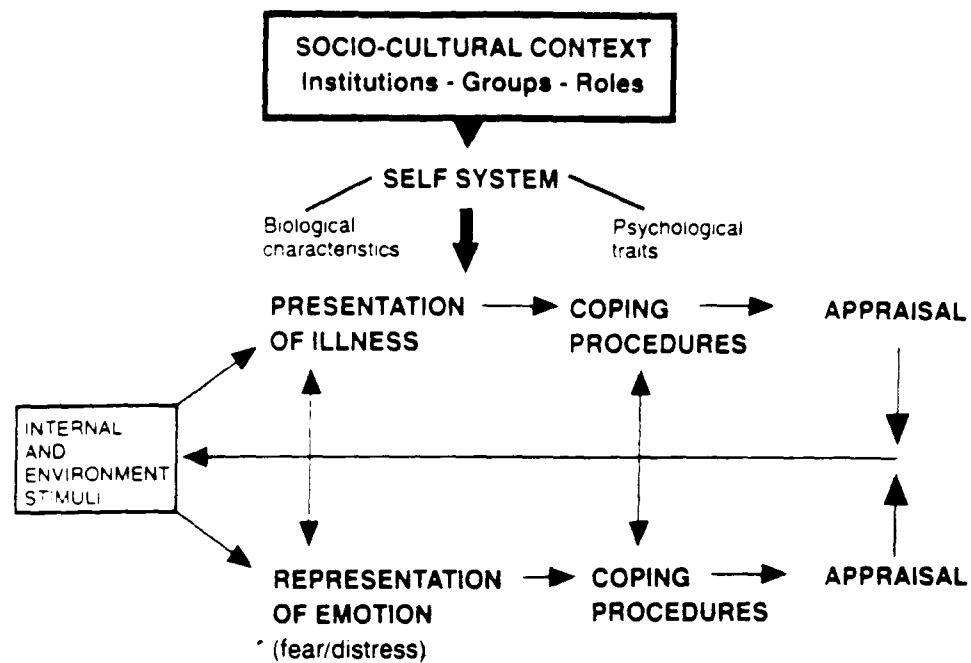


Figure 1. Leventhal's self-regulatory model of illness (Adapted from Leventhal et al, 1992)

Bauman, Cameron Zimmerman & Leventhal (1989) have found evidence for the illness identity and the cause components of illness representations and their effect on information processing and coping. Bishop and Converse (1986) found evidence suggesting that people process illness-relevant information according to prototypic schemata. They also found support for the construction of new schemata when information does not fit with existing schema. This links with the work on functionalist accounts of children's development of illness concepts (Carey, 1985) which also conceptualises that illness relevant information is schematically represented.

Lacroix, Martin, Avendano & Goldstein (1991) have demonstrated that these schemata in adults are relatively independent of objective disease severity and play a role in guiding both information processing and illness related behaviour. Leventhal et al (1992) suggest that discrepancies occur between the formal and concrete levels of information processing with the concrete and symptomatic aspects more persuasive guides to action than the abstract knowledge a person has about a specific illness. This would help to explain low adherence rates within chronic conditions and highlights the possible difficulty a person may have integrating knowledge from direct bodily experience with the abstract knowledge provided by health practitioners. This account would offer some explanation for the fact that knowledge has a variable influence on an individuals' illness management.

In adult studies patient's illness representations have been examined using the Illness Perceptions Questionnaire (IPQ) (Weinman et al., 1995). The method has been found to distinguish between and be sensitive to the perceptions of patients with various illnesses. In a study with Chronic Fatigue Syndrome patients support was found for the self-regulatory function of illness representations in determining coping. However, illness representations were more strongly predictive of levels of distress and disability than coping (Moss-Morris, Petrie & Weinman, 1996). In work with adult asthmatics (Schembri Wismayer, 1995) found that illness representation and coping explained a significant proportion of the variance in outcome as measured by anxiety, mood and asthma control. However in line with Moss-Morris et al (1996) few associations were

found between coping and illness representations. Both authors suggest that illness representations may have a direct effect on mood and adjustment which are not mediated by coping. No studies, to date, have considered illness representations amongst children within the self-regulation model.

1.5. Rationale

From the literature reviewed, it would appear that asthma can have a severe impact on the quality of children's lives. However, research findings suggest that the impact is variable. Reasons have been advanced to suggest that some of this difficulty is due to the different accounts that are used to gain information about the child and the different ways in which outcome is measured. Health related Quality of Life from a child's perspective has shown that a child's subjective accounts may offer a greater understanding of this variable impact.

Despite advances in medical treatment and ways to assist children in appropriate self-management many children fail to achieve a reasonable level of asthma control and suffer unnecessarily. Lack of knowledge has been postulated as a reason why children fail to manage. Yet, the relationship between knowledge and self-management is not clear.

Although it would seem that children's understanding of illness does evolve in some systematic fashion, stage type approaches have failed to account for the variability in children's understanding of illness. It remains unclear to what extent their understanding translates into management of their illness and outcome.

This study aims to take a child's perspective and consider if a self-regulation model, which has shown considerable promise with adults, may provide a more individual approach to children's perceptions of their asthma and how these may influence self-management and outcome.

1.6. Aims.

1. To provide data on two age groups of children (8-11 years) and (12-16 years) with asthma and explore the content of children's illness representations.
2. to evaluate whether a newly developed measure of Illness Perceptions (IPQ) can be used with a child/adolescent population.
3. to examine differences in illness representations, management, quality of life and control amongst the two age groups
4. to explore associations between children's illness representations, management behaviours, quality of life and asthma control
5. to assess the relative importance of the contributions of illness representations and management to quality of life and control

6. to explore the relationships between knowledge of asthma and management.

1.7. Hypotheses.

1: Age groups will differ on measures of a) illness Representations b) knowledge c) management. (Two- tailed)

2: Illness Representations will be related to a) knowledge b) management c) asthma control d) quality of life. (Two- tailed)

3: There will be no relationship between knowledge and a) management b) quality of life c) asthma control. (Two-Tailed).

4: Good self-management will be associated with better a) asthma control and b) a higher perceived quality of life. (One-Tailed)

5: Illness representations will be more strongly related than knowledge to quality of life and asthma control . (One- tailed)

6: Illness representations will be more strongly related to a) asthma control and b) quality of life than management (Two- tailed)

2. METHOD

2.1. Ethical approval

Ethical approval was gained for the study from the responsible community trust. A copy of the letter granting ethical approval is included as Appendix 1 .

2.2. Design

The study employed a between and within group design to compare illness representations, knowledge, management, asthma control and quality of life measures with children in the age groups 8-11 years and 12-16 years. Five children from each age group participated in a test re-test sample and were interviewed again at a three to four week interval.

A number of demographic factors such as gender, duration of asthma and material deprivation were controlled for to ensure that differences observed between age groups were not due to the effects of such factors.

A correlational design was used to test for associations between illness representations, management, knowledge, control and quality of life measures and to assess the relative contribution of illness representations, knowledge and management to asthma control and quality of life.

2.3. Participants

Children between the ages of 8-16 years who had been diagnosed with asthma and prescribed medication were included in the study. A test of verbal ability was performed and children who would have had difficulty with the protocol, due to low verbal ability, were excluded.

Asthma severity was assigned on the basis of prescribed medication as recommended by the British Thoracic Society's (1990) guidelines. This method was adopted to ensure that severity was not confounded by other factors such as asthma control. The Monthly Index of Medical Specialities (MIMS, 1995) a pharmaceutical publication was used to determine participants severity level. Three severity ratings were used:

1. **Mild** : Inhaled bronchodilator only.
2. **Moderate**: Inhaled bronchodilator plus inhaled sodium Cromoglycate 10-20 mgs or regular low dose inhaled steroids e.g. 50-200 micrograms Beclomethasone or Budesonide twice daily.
3. **Severe**: Inhaled bronchodilator plus regular high dose of inhaled steroids 400-800 micrograms daily and/or oral steroid therapy.

Socio-economic status of the family was classified using a measure of material deprivation (lack of economic resources) based on home tenure and car ownership . This is not a standard instrument. However, in longitudinal population surveys the two variables together account for more variability in mortality rates than conventional measures of social class; with those reporting home ownership and access to two or more cars to have better health outcomes and those in rented accommodation with no car to have the worst. Hayes (1991) suggests that it provides a better measure of socio-economic status related to health than conventional methods based on occupation.

This method yields a range of six possibilities which were coded as below with 6 signifying greater economic resources and 1 lower.

- 6: Own house/flat, two plus cars
- 5: Own house/flat, one car.
- 4: Own house/flat, no car.
- 3: Rented house/flat, two plus cars.
- 2: Rented house/flat, one car.
- 1: Rented house/flat, no car.

All participants were recruited via General Practitioners (GPs) a total of seven GP multi-practices participated in the research. A total of 170 letters were sent to parents

of asthmatic children (Appendix 2). Of these forty- seven parents agreed to participate, which represents a response rate of 27.6 percent. Of the returned responses four were excluded because the children were no longer being treated for asthma. The data on two participants was not gathered due to a low verbal ability as determined by the British Picture Vocabulary Scale. A total of 41 valid data sets were obtained, with 18 children aged between 8-11years and 23 children aged between 12-16 years. The demographic characteristics of the sample are shown in Table 1 and 2.

Table 1: Demographic Characteristics of Participants

Group	Number	Male	Female	Age range yrs	Mean age (SD) yrs	Mean duration of asthma (SD) yrs
Group 1	18	16	2	8-11	9.72 (SD=1.18)	6.2 (SD=2.94)
Group 2	23	11	12	12-16	13.61 (SD=1.27)	8.96 (SD= 4.42)

Table 2: Severity Group and Material Deprivation of Participants

GROUP	MILD	MODERATE	SEVERE	MATERIAL DEPRIVATION					
				1	2	3	4	5	6
Group 1	5	13	0	1	2	0	1	9	5
Group 2	2	18	3	0	0	0	3	10	10

2.4. Measures

Measures were developed or chosen to obtain children's self-reports, with the exception of Asthma Control which relied on information from parents.

Illness Perception Questionnaire (IPQ), (Weinman, Petrie, Moss-Morris & Horne, 1995)

The IPQ in the adult form, is a thirty-nine item self report scale developed to measure illness representations in a variety of conditions. Items were derived empirically to reflect five theoretical components of illness representation: identity, consequences, control/cure, timeline and causes. The adult version has been standardised in a number of large studies that have included asthma (Moss-Morris et al, 1995) and it has established psychometric properties with internal subscale consistency ranging from 0.71 to 0.81. Test-retest reliability coefficients for the subscales ranged from 0.49 to 0.84 at one month and 0.33 to 0.60 at three months significant at the $p \leq 0.01$ level.

The measure was adapted for use with children for this study in consultation with the measures author and a Consultant Clinical Child Psychologist. The adapted version aimed to reduce the complexity of the language of the questions and required responses as well as include items in the cause subscale that would reflect noted developmental changes in the way children make attributions about illness. The measure was used as a structured interview and responses were made either verbally or by pointing to a laminated response sheet with responses written in large, bold lower case letters.

A pilot study was undertaken with the adapted measure and a total of six children three from each age group were asked to generate their own beliefs about the cause of asthma and comment on the understandability of the questions. During these interviews probes were used to clarify the child's understanding of the questions. As a result of the pilot study, reversal questions were omitted and more abstract concepts of chance or fate were similarly changed to be more concrete. Internal reliability and test re-test analysis of this adapted measure is presented in the results section

The measure used (Appendix 3) comprised of fourteen items related to illness identity which included items that reflect common symptoms of asthma such as coughing and wheezing and side effects from the medications used such as feeling shaky and a dry mouth. Participants were asked to rate the frequency with which they experienced symptoms on a four point scale ranging from never, a little bit, quite a lot, to always.

The remaining twenty-five items required participants to state the extent to which they thought the question described "how they feel/ what they think" about their asthma on a five point scale ranging from; definitely yes, perhaps yes, not sure, perhaps no and definitely no. Six of these items deal with perceived consequences of their illness, five with perceived degree of control/cure, three items measured the perceived timeline or duration of the illness and eleven items were concerned with attributions about the cause of their illness.

Illness identity scores gave a weighted symptom score ranging. The scores for the remaining subscales were calculated by summing the scores on the items for each subscale and taking a mean for each subscale. The measures yielded and used from the IPQ were as follows:

1. Weighted illness identity score from zero to forty-two a higher score indicating a greater illness identity.
2. Illness consequence score from one to five with higher scores indicating a greater perceived illness consequence.
3. Illness control/cure from one to five with higher scores indicating a greater perceived control over and cure of the illness.
4. Illness timeline score ranging from one to five with higher scores indicating longer perceived timeline or duration of illness.

Illness cause scores ranging from one to five with higher scores indicating a stronger belief in factors as causative on dimensions of : environmental pollution, luck, others, hereditary, stress, diet, own behaviour, poor past medical care, germ or virus, state of mind and immanent justice (being naughty).

Knowledge (Appendix 4)

Knowledge of asthma was assessed with the 20 item children's version of the Parcel Knowledge of Asthma Questionnaire (Parcel, Nader & Tiernan, 1980). The measure tests for knowledge of: basic concepts about the nature of asthma and general management procedures. Children are asked to answer each question as true or false, correct answers are summed resulting in a potential range of zero to twenty, with higher scores indicating greater knowledge. The Kuder-Richardson coefficients of internal consistency for the scale were 0.56 on the child scale and 0.88 for the adult scale. The scale is sensitive to change in knowledge over time as documented by a large educational intervention study (Parcel et al., 1980). In view of the low reliability of the child scale a further response of "don't know" was included for this study to try and improve the measure's reliability. This was based on the consideration that it is possible that children may not know all the answers and thus false positives, as would be incurred by opportunist guessing, would be eliminated. To document the measures reliability following this change in administration, internal reliability and test- retest analysis was performed, and reported in the results section.

Verbal ability (Appendix 5)

Verbal Ability was assessed using the British Picture Vocabulary Scale (BPVS) Short Form, (Dunn, Dunn, Whetton & Pintilie (1982). The BPVS is designed to measure acquired receptive vocabulary for standard English. The measure is used with pre and school-aged children to detect language impairment and scholastic aptitude for children who have standard English as their language of the home. The test provides a non-threatening assessment tool as responses can be made by pointing and does not require the child to read or write.

In this study the short form was used which consists of thirty-two items. Raw scores were converted into standardised age equivalent scores. The standard mean score of 100 was used with a standard deviation of 15. Split half reliability studies have found a median reliability for the short form of .80 with a range of (.74- .88). The measure has good reported content and construct validity.

Verbal ability scores were used to screen out children with low verbal ability who may have found the interview challenging. Children who scored below one standard deviation i.e. cut off point 85 were excluded from further data collection. Verbal ability was also compared between groups to allow for differences, if found, to be controlled for in the analysis.

Management (Appendix 6)

Children's management of their asthma was assessed using a measure developed for the study. The measure was based on the work of McNabb, Wilson, Pessano & Jacobs (1989) who, using a critical incident analysis, identified core competencies in asthma management relating to: preventative behaviours such as avoiding situations or known triggers to wheezing, intervention behaviours such as the use of inhaled medication, compensatory behaviours such as using asthma to get your own way and external controlling factors which relate to the extent adults interfere with self-management. The Asthma Behavioural Assessment Questionnaire, which was developed from this research, by the American Institute for Research (1984) was unavailable for use.

In the developed measure five questions addressed preventative behaviours, seven addressed intervention behaviours and six compensatory behaviours. External controlling factors were not considered to represent daily strategies that children use to manage their asthma and were not included. Children were asked to rate on a five point scale (ranging from never to always) how often they engage in the behaviour. Scores were summed and a mean score obtained for each subscale with a range of 1-5. Higher scores indicate greater management competency.

In previous research (Kieckhefer, 1987) a total management score has been used with a reliability of (Cronbach $\alpha = 0.72$). Construct validity has been supported as scores have risen in experimental groups exposed to asthma self-management programmes (McNabb et al., (1986). In the current study an internal and test-retest reliability analysis was performed and reported in the results section.

Quality of life

Childhood Asthma Questionnaires. CAQ-B & CAQ-C. (Christie, Sowden and West, 1993) (Appendix 7 & 8)

The Childhood Asthma Questionnaires are one of the few child-centred, disease specific measures available and were designed to be used as outcome measures in primary and secondary health care settings. The questionnaires seek to quantify children's perceptions of quality of life on a number of dimensions. Three versions are available; the CAQ-A for use with children aged 4-7 years, the CAQ-B for ages 8-11 and the CAQ-C for children aged from 12-16 years. In this study CAQ-B and CAQ-C were used.

CAQ-B

CAQ-B includes four factors; active quality of life, passive quality of life, subjective severity and distress. Children are required to colour in boxes to reflect how often they engage in certain activities and to colour in faces to depict how they feel when

engaged in the activity. Active Quality of life addressed pastimes such as swimming and playing out of doors and passive quality of life includes items relating to sedentary activities such as reading. Items are scored as one for the unhappiest face and five for the happiest face with high scores representing high levels of quality of life.

The asthma related questions form two subscales, subjective distress and severity. The distress subscale asks how children feel about asthma related symptoms such as coughing and wheezing, high scores are associated with higher levels of distress. The severity subscale relates to the frequency of symptoms. and a self report severity score is obtained with high scores indicating greater perceived severity.

CAQ-C

The CAQ-C was developed for a teenage population and includes 41 items yielding five factors : active quality of life, teenage quality of life, severity, distress and reactivity. Active Quality of life and Teenage Quality of Life are conceptually similar to the CAQ-B although they relate to age specific activities of this group. Distress and severity are the same psychological constructs as the younger age group measure. Reactivity is however different and relates to increased reactivity to environmental triggers such as smoking and dealing with other peoples smoking. Although reactivity is not comparable across the two age groups it was included in the study to consider the effects of illness representations on these important issues for adolescents. The

administration format of the CAQ-C requires the older children to put appropriate numbers at the side of the questions using a coding key.

The CAQ-B has undergone extensive piloting and psychometric exploration and is believed to be sensitive to change over time following intervention. Internal reliability are reported for the CAQ-B of between Alpha 0.44 - 0.82, and Alpha 0.50-0.80 for the CAQ-C. Test-retest reliability coefficients at a three week interval revealed stability over time in both measures with a range of 0.73 - 0.75 for the CAQ-B and 0.73 - 0.84 for the CAQ-C.

Background information sheet: Information obtained from parents (Appendix 9)

The parental section of the CAQ-B, which is not used to compute the child's quality of life scores, was used to obtain information about the child's age, duration of asthma and number of other children in the family. Questions 5, 6, 7 and 8 related to asthma control and asked about the number of times their child had needed to go to the GP, Casualty, the frequency of days lost from school and the number of times they had been woken at night due to their child's asthma during the last two months. These were rated on four and five point scales and a total score was used to measure asthma control, with high scores indicating lower asthma control. The measures were combined due to their logical relationships and to improve the range of the measure.

The CAQ protocol was used in its complete form and other questions were not used in the analysis. Question 10 asked parents to rate their perception of the current severity of their child's asthma on a three point scale ranging from mild to severe. Question seven asked parents to rate how well controlled they considered their child's asthma was currently on a three point scale. Question eleven asked parents to rate on a four point scale the extent to which they considered that their child's asthma had recently affected the rest of the family.

Two further questions were added by the author and included the rating of material deprivation and a section that required parents to list their child's medication including name of drug, dose and frequency of administration. This information was used to assign asthma severity as described previously.

Summary of measures yielded and used in the study

- 1: **Age** (years)
- 2: **Gender** (male / female)
- 3: **Duration of asthma** (years)
- 4: **Severity** (mild /moderate /severe)
- 5: **Asthma Control** (range 4-17, high scores indicated lower asthma control)
- 6: **Material deprivation** (range 1-6, higher indicating greater economic resources)

7: **Verbal ability** represented as a standardised score of verbal ability.

8: **Knowledge** range 0-20 with high scores indicating greater knowledge.

9: **Management:**

Preventative behaviours (Range 1-5, high scores indicate high frequency of preventative behaviours)

Intervention behaviours (Range 1-5, high scores indicate high frequency of intervention behaviours)

Compensatory behaviours (Range 1-5, high scores indicate greater adaptive compensatory behaviours)

12. Illness Perceptions Questionnaire

Symptom scores for each of the following: Chest pain, feeling sick, hard to breathe, tired, sore head, upset tummy, can't sleep, dizzy/giddy, coughing, wheezing, butterflies in chest, feeling shaky, can't think straight and dry mouth.

Weighted illness identity scores (high scores indicate greater endorsement of symptom frequency)

Illness consequences score (high scores indicate greater perceived consequences of asthma)

Illness control/ cure score (high scores indicate greater perception of control over asthma)

Illness timeline scores (high scores indicate greater perceived timeline/duration of asthma)

Illness cause scores for each of the following: luck, others, hereditary, stress, diet, environmental pollution, own behaviour, poor past medical care, germ or virus, emotional state of mind and immanent justice (being naughty). High scores indicate greater belief in factor as causative.

13. Quality of Life

CAQ-B

- Distress (DIS) six questions with a range 9(low) to 30 (high)
- Active quality of life (AQOL), seven questions range 7 (low) to 35 (high).
- Passive quality of life (PQOL) four questions range 4 (low) to 20 (high).
- Severity (SEV) six questions range 6 (low) to 23 (high).

CAQ-C

- Distress (DIS) 11 questions range 12 (low) to 60 (high)
- Severity (SEV) 9 questions range 9 (low) to 34 (high)
- Active quality of life (AQOL) 5 questions range 8 (low) to 36 (high)
- Teenage quality of life (TQOL) 5 questions range 5 (low) to 23 (high)
- Reactivity 5 questions range 5 (low) to 24 (high)

2.5. Procedure

2.5.1. Recruitment of participants

General Practitioners were asked to identify potential participants from their records and a standard letter, prepared by the author, was sent to parents from their GP. The letter included information about the study and what participation would involve. Parents were offered a contact number to allow further information to be sought before they made a decision to participate or not. A response slip and a pre-paid envelope was enclosed.

Parents who returned the response slip were contacted by telephone to arrange a home visit. The initial contact was used to clarify the nature of the interview and to state that they would be visited by the named researcher only, who would provide identification.

2.5.2. Interviews.

Interviews included a general introduction to the study and particular attention was given to discuss the study with the child. Written consent was obtained from the parent (Appendix 10) and the child's consent was sought verbally. The option to stop at any time was explained to the child and parent. Time was spent talking with the child to put them at their ease. The content of this varied but often centred around school and interests. The child and parent were advised that individual responses would not be offered to other persons. This was done to reduce the possibility of a child overly reporting positive behaviours. The parents were asked to fill in their part of the interview whilst their child worked with the author. If parents were clearly keen to remain with their child, this was not discouraged. The format was of a structured interview and the author read out the questions to each participant. This was used to enable, more qualitative discussion and rapport to be facilitated. The exception was the quality of life measure for the older age group which was self-administered.

Verbal ability

The scale was completed first to allow the interview to be curtailed if the child scored below the cut off point. Children were required to either respond verbally or to point their choice of picture. Feedback on their performance/ ability was not given although positive comments were offered on completion. Two children obtained scores well below the cut off point. This was handled at the time by remaining with the child and

engaging them with the first part of the CAQ-B which involved colouring in the faces related to everyday activities. This was noted throughout the study to be an activity that the participants enjoyed and could be presented in such a way as to not require extensive comprehension skills.

Knowledge

The asthma knowledge measure was completed next to allow a baseline of knowledge to be obtained before asthma relevant information was discussed. Children were encouraged to use the don't know option rather than guess. The easy true/false/don't know response also allowed children to feel at ease with this type of interview.

Management

The management measure was then administered, probes were used throughout to provide a check on the child's understanding. On the questions that were clearly asking children to be very honest in the face of knowledge about a more desirable behaviour, the questions were phrased to attempt to eliminate a value judgement. If parents were keen to remain, the child was invited to read these questions. For the older group the measure was self-administered if parents were present.

Illness perceptions

The Illness Perception Questionnaire was administered penultimately to allow for asthma related information to be salient to the child. The required responses were explained.

Quality of life

The Quality of life measure was administered last. The faces and boxes were explained and participants in the younger age group were invited to use the felt tips provided and choose colours and ways of making their response on the forms as they liked i.e. colour in the whole block or make monster faces/ add hair etc. around the ones given. Children were very creative in this section and appeared to enjoy the task.

Re-Test Interviews

At re-test the same order and method was adopted.

Debriefing of participants

On completion of the interview each child and parent was thanked and confidentiality regarding the data was reiterated. The measures used were outlined and any questions answered. Information was given about the anticipated time scale for a summary of results being available at their GP surgery for those who wanted this. Some parents raised issues about the medical management of their child's asthma and were directed to seek advice and information from their GP or asthma clinic nurse.

Willingness and permission to be further contacted for participation in the retest sample was sought from parent and child, information was given about the expected time scale and level of involvement. Each parent received an information sheet (Appendix 11) with a contact number and parents were encouraged to ask questions at a later date if they wished.

2.6. STATISTICAL ANALYSIS

The data generated were a mixture of nominal, ordinal, summed ordinal and interval. Nominal data included gender, severity group and material deprivation. Ordinal data included asthma control, illness representations, and quality of life. Interval data included verbal ability, knowledge, age, duration of asthma and management.

In view of different levels of data both parametric and non-parametric tests were used. For the ordinal and interval data the Levene Test of homogeneity of variance was used to determine suitability for parametric analysis. In the vast majority of cases there was homogeneity of variance and, therefore, parametric analysis was deemed appropriate. (Full results of Levene statistics are found in (Appendix 12)).

The analysis was divided into four stages:

Stage 1: Reliability analysis of measures developed or adapted for this study and analysis of re-test data. The Cronbach Alpha statistic was used to determine the scale's internal reliability and intra- class correlations were used to calculate the measures' test- retest reliability. Measures undergoing reliability analysis were the IPQ subscales. The ten cause questions do not form a distinct scale and were therefore not included. The management scales developed for this study, and the Knowledge Questionnaire.

Stage 2: Inter-correlations between IPQ subscales for both groups were performed.

Stage 3: Descriptive statistics were produced for both age groups. The groups were compared using Chi Square and Independent T-tests on both dependent and independent measures.

Stage 4: Pearson correlations were used to test for associations between illness representations, knowledge, management and the outcome measures of Quality of life and Asthma Control within each of the groups. This parametric test was also used on nominal data to ensure consistency of analysis. Scattergrams were performed to confirm that the relationships were linear and not affected by outlying cases. Non-parametric analysis using Kendall C Test was used to analyse dichotomous data such as gender.

Stage 5: Significant correlations from the univariate analysis were entered into a series of hierarchical multiple regression analysis to determine the relative contributions of Demographic indices, illness representations, knowledge, management to the outcome measures of quality of life and asthma control.

All analyses were carried out using the Statistical Package for Social Sciences for Windows, Version 6.0.1 (SPSS Inc., 1993).

In view of the exploratory nature of the study it was decided to set significance levels at $P \leq 0.05$ level.

3. RESULTS

The results are presented in the following order:

- 3.1.** Reliability analysis for the measures developed or adapted for this study and inter- correlations between the IPQ subscales for each group.
- 3.2.** Descriptive statistics for each group and the results of comparative tests between groups.
- 3.3.** Univariate tests of associations between demographic indices, illness representations and outcome measures.
- 3.4.** Univariate tests of associations are then presented between illness representations and management, knowledge, asthma control and quality of life measures.
- 3.5.** Univariate tests of associations between knowledge and management, asthma control and quality of life.
- 3.6.** Associations between management and asthma control and quality of life.
- 3.7.** Multiple regression analysis comparing the relative contributions of demographic indices, illness representations, management and knowledge to quality of life and asthma control measures.

All significance levels quoted are at the $p \leq 0.05$ level one and two-tailed.

3.1. RELIABILITY OF MEASURES

Illness Representations Questionnaire(IPQ)

The results of the reliability analysis for the IPQ scales are presented in Table 3.

Table 3: Internal and Test-Retest Reliability for the IPQ scales.

SCALE	GROUP1 TIME 1 Alpha	GROUP1 TIME 2 R	GROUP2 TIME 1 Alpha	GROUP 2 TIME 2 R
Illness Identity	.6699	$r=.7696$.6204	$r=.3278$
Illness consequences	.7822	$r=.8414$.6754	$r=.3792$
Control/Cure *	.4653	$r=.7559$.3765	$r=.2848$
Control/Cure (amended)	.6647	$r=.9449$.5894	$r=.3527$
Illness Timeline	.5658	$r=.8627$.5514	$r=.2560$

The reliability of the IPQ scales was variable although comparable to other studies using the measure in adults (Moss-Morris,Petrie & Weinman,1996). The control/cure scale * was found not to demonstrate a good internal reliability with a Cronbach Alpha of .4653 for group 1 and .3765 for group 2. From examination of the internal structure using factor analysis, one item, question 3 (which related to a belief that if the child's asthma got better or worse it was a matter of luck) was reducing the Control/Cure scale's overall reliability. This question was excluded from further analysis and as shown in Table 3 the reliability of the scale improved for both groups.

The scales on the whole were more consistent with the younger Group 1 over the two times of testing. For the older Group 2 the scales were found not to be consistent at time two with low correlations. In view of the exploratory nature of this

study all IPQ scales were included in further analysis although the results obtained must be treated cautiously.

Inter-correlations between IPQ Subscales

Inter-correlations between IPQ subscales were performed for both groups. Results are presented in Tables 4 & 5.

Table 4. Inter-correlations between IPQ Subscales for Group 1

IPQ Subscale	Consequences	Control/Cure	Timeline
Illness Identity	r=.3237 p=.190	r=.3173 p=.200	r=.2834 p=.254
Consequences		r=.2150 p=.391	r=.2507 p=.316
Control/Cure			r=.0623 p=.806

* p < .05; ** p < .02; *** p < .001.

Table 5. Inter-correlations between IPQ Subscales for Group 2.

IPQ Subscale	Consequences	Control/Cure	Timeline
Illness Identity	r=.3997 p=.059	r= -.2498 p=.250	r=.1607 p=.464
Consequences		r= -.1060 p=.630	r=0.554 p=.802
Control/Cure			r= -.5057 p=.014*

* p < .05; ** p < .02; *** p < .001.

As shown in Tables 4 & 5 there were no significant correlations between IPQ subscales in Group 1. There was a significant negative correlation between the older children's perceived duration of illness and Control/Cure, which would indicate that the less the perceived duration of asthma the greater belief in the condition as controllable and curable.

Management

The results on the reliability analysis on the management scales are presented in Table 6. The scale was comprised of three subscales that related to preventative, intervention and compensatory behaviours as suggested by McNabb et al. (1986). The notion of core competencies was not developed by psychometric analysis. When analysed for this study the scales did not show good reliability.

Table 6. Internal and Test-retest Reliability Analysis for the Management Subscales

SCALE	Group 1 Time 1 Alpha	Group 1 Time 2 R	Group 2 Time 1 Alpha	Group 2 Time 2 R
Preventative	.3232	r=.5688	.3914	r=.5894
Intervention	.3274	r=.4462	.2015	r=.4462
Compensatory	.0074	r=.2473	.5684	r=.6892

To examine the internal structure of the management subscales an exploratory factor analysis was performed using a principal component analysis with a three factor solution and varimax rotation. Table 6 shows that the scales built by this method appeared to fit a rather different picture than that suggested by McNabb et al (1986), with scale one relating to adherence with medication, scale two behavioural strategies and scale three to social management. Eigenvalues for the created scales are shown in Table 7.

Table7. Eigenvalues for Each of the New Subscales

SCALE	GROUP 1	¹ %	GROUP 2	¹ %
Adherence	3.678	24.5	3.128	20.9
Social Management	2.344	15.6	2.301	15.3
Behavioural Strategies	2.002	13.3	1.824	12.2

¹ % depicts percentage of variance

Internal and Test-retest reliability analysis was performed on the newly constructed scales. The results are presented in Table 8.

TABLE 8. Internal and Test-retest Reliability for the New Management Scales

SCALE	GROUP1 TIME 1 Alpha	GROUP 1 TIME 2 R	GROUP 2 TIME 1 Alpha	GROUP 2 TIME 2 R
Adherence	.6795	r=.9091	.6031	r=.3591
Behavioural Strategies	.3781	r=.6472	.2933	r=.4723
Social Management	.3726	r=.5894	.4494	r=.4428

As shown in Table 8 the internal and test-retest reliability of the new scales depict that the behavioural strategies and social management scales have low levels of reliability in both groups. Due to this only the adherence scale was included in further analysis.

Knowledge

The Parcel Knowledge Questionnaire had a reported reliability of (Alpha=0.56) for children (Parcel et al., 1980). The reliability of present results is presented in Table 9.

Table 9. Internal and Test-retest Reliability for Knowledge.

Measure	GROUP1 TIME1 Alpha	GROUP1 TIME 2	GROUP 2 TIME 1 Alpha	GROUP 2 TIME 2
Knowledge	.2329	r=.8104	.7393	r=.3750

As can be seen in Table 9, following the change in administration the measures' reliability was reduced for the younger age group and increased for the older group. The test-retest data, however, showed that the measure was stable over time for the younger children but not for the older group.

Asthma Control

Internal reliability for the Asthma Control measure is presented in Table10.

Table 10. Internal Reliability on Asthma Control.

	GROUP 1	GROUP 2
Asthma Control	Alpha = .4592	Alpha = .8412

As shown in Table 10 the measure achieved a good level of reliability for the older children but a low reliability for the younger children.

3.2.DESRIPTIVE STATISTICS AND COMPARISONS BETWEEN GROUPS

Demographic Characteristics of Participants

Chi Square tests were performed on nominal demographic data between groups, results are shown in table 11.

Table 11. Results of Chi Square Tests for Gender and Severity Group

VARIABLE	X ² VALUE	SIGNIFICANCE (p)	DEGREES OF FREEDOM
Gender	4.359	0.036 *	1
Severity group	4.550	0.102	2
Material deprivation	5.186	0.268	4

Significant at * p < .05; ** p < .02; *** p < .001.

As shown in Table 11 there were significant gender differences between the groups with more girls in the older group. The results for severity group and material

deprivation were not significant but must be treated with caution as there were a number of cells with minimum expected frequency of less than five.

Verbal Ability

Descriptive statistics and an Independent T-Test were used to describe and compare verbal ability between groups. Results are presented in Table 12.

Table 12. Mean Scores and Comparisons of Verbal Ability in Group 1 and 2

VARIABLE	GROUP 1	GROUP 2	T-Value	SIGNIFICANCE	(D.F.)
Verbal Ability	107.61 (SD=12.27)	105.48 (SD=11.48)	.57	p= .574	39

Significant at * p < .05; ** p < .02; *** p < .001.

As can be seen in table 12 groups did not differ significantly on age corrected verbal ability.

Knowledge

Descriptive statistics and Independent T-Tests were performed to describe and compare knowledge between the two groups. Results are presented in Table 13.

Table 13. Mean Scores and Comparisons on Knowledge in Group 1 and Group 2

VARIABLE	GROUP 1	GROUP 2	T VALUE	SIGNIFICANCE	(D.F.)
Knowledge	15.67 (SD=2.00)	17.52 (SD=2.19)	-2.79	p=.008 **	39

Significant at * p < .05; ** p < .02; *** p < .001.

Table 13 demonstrates that the older children were significantly more knowledgeable than the younger children.

Illness Representations

The mean scores and Standard Deviations are presented for the illness representation subscales for each group. Independent T-Tests were used to compare the groups on these subscales. The results are presented in Table 14.

Table 14. Means Scores for Each of the IPQ Subscales and Results of T-Test Comparisons Between Group1 and 2.

IPQ SUBSCALE	GROUP 1	GROUP 2	T Value	Sig	(D.F.)
Illness Identity	15.78 (SD=4.61)	14.65 (SD=4.12)	.82	p=.415	39
Consequences	2.61 (SD=.91)	2.13 (SD=.80)	1.80	p=.080	39
Control/Cure	3.83 (SD=.75)	3.86 (SD=.60)	-.12	p=.905	39
Timeline	2.86 (SD=.74)	3.14 (SD=.79)	-1.15	p=.257	39
Pollution	3.50 (SD=.71)	3.57 (SD=1.12)	-.22	p=.831	39
Others	1.56 (SD=.86)	1.65 (SD=.95)	-.32	p=.750	39
Poor medical care	1.61 (SD=1.20)	1.00 (SD=0)	-2.17	p=.045 *	17
Hereditary	3.56 (SD=1.34)	3.61 (SD=1.5)	-.12	p=.907	39
Stress/worry	1.61 (SD=.92)	1.83 (SD=1.19)	-.63	p=.531	39
State of mind	1.33 (SD=.69)	1.57 (SD=.95)	-.88	p=.387	39
Food allergy	1.89 (SD=.90)	2.39 (SD=1.3)	-.39	p=.172	38.48
Being naughty	1.00 (SD=0)	1.00 (SD=0)	-----	-----	-----
Bad luck	2.00 (SD=1.33)	2.09 (SD=1.41)	-.20	p=.842	39
Poor self care	2.00 (SD=.91)	1.78 (SD=1.0)	.68	p=.499	39
Germ/Virus	2.94 (SD=.94)	2.09 (SD=1.28)	-2.48	p=.018 **	38.88

Significant at * p < .05; ** p < .02; *** p < .001.

The illness identity subscale scores were moderate suggesting that these symptoms occurred less frequently. Both groups viewed themselves as having a moderate degree of control over their asthma. There were no significant differences between groups on perceived timeline. The consequences of asthma were viewed by both groups of

children as mild to moderate. Table 14 also shows that for both groups causes of asthma were most frequently attributed to hereditary reasons and then pollution. The younger group considered that a germ/virus explanation was the next most likely cause and the older group viewed reaction to food as the next most likely cause. Bad luck was viewed as a possible cause in both groups. The least likely causes were state of mind or stress and no children perceived being naughty as a likely cause.

The results of independent T-Tests comparing age groups on the IPQ subscales found that the groups differed significantly on two cause questions. None of the older children endorsed poor past medical care as causal and thus the groups were significantly different. A belief in a germ/virus explanation was significantly different with younger children more strongly endorsing this belief..

Management

The results of mean scores and Independent T tests for adherence in both groups are shown in Table 15.

Table 15. Mean scores and Comparison between Groups on Adherence.

SUBSCALE	GROUP 1	GROUP 2	T VALUE	SIG	(D.F.)
Adherence	4.11 (SD=.71)	3.66 (SD=.84)	1.81	p=.078	39

Significant at * p < .05; ** p < .02; *** p < .001.

As shown in Table 15 there were no significant differences between groups on adherence and the mean adherence for both groups would suggest good levels of adherence (range 1-5).

Quality of Life Measures

Table 16 shows the mean scores on the Quality Of Life measures. Comparative analysis was not possible due to the different ranges of the scales and different measures between groups.

Table 16. Mean Scores on Quality of Life Measures

VARIABLE	GROUP 1	GROUP 2
Active Quality of Life	28.89 (SD=3.27)	28.78 (SD=3.86)
Passive Quality of Life	16.61 (SD=1.69)	*
Teenage Quality of Life	*	12.62 (SD=3.31)
Subjective severity	11.28 (SD=2.72)	17.7 (SD=3.16)
Subjective Distress	23.33 (SD=4.17)	38.17 (9.17)
Reactivity	*	29.39 (SD=3.83)

* Scale not applicable to Group.

As depicted in Table 16 the younger children in Group 1 had a high perceived quality of active and passive life and perceived themselves as having a moderate level of severity and a high to moderate level of distress. For the older children in Group 2 there was a high level of perceived active quality of life and a moderate level of perceived teenage quality of life. Perceived severity and distress for Group 2 was moderate.

Asthma Control

Results for asthma control are presented in Table 17 with the frequency and percentages of children who, due to asthma, lost school days, disturbed their parents at night, visited their GP and attended casualty.

Table 17. Frequency and Percentages on Components of Asthma Control for Each Group.

VARIABLE	GROUP 1		GROUP 2	
Children who lost School Days	6	33.4%	10	43.5%
Children who disturbed parents at night	7	38.9%	5	21.7%
Children who visited GP	6	33.4%	7	30.4%
Children who attended casualty	0	0%	0	0%

As shown in Table 17 with each item there were parental reports of children missing school, disturbing them at night and requiring to visit their GP in the two months prior to responding. No children in this sample had been admitted to casualty during the last two months. The means and comparisons for each group on total asthma control are presented in Table 18.

Table 18. Means and Comparisons for Asthma Control

	Group 1	Group2	T- Value	Sig	(D.F.)
Asthma Control	5.66	5.391	.49	.628	39

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 18 there were no significant differences between the groups on Asthma Control. Asthma control was good (range 1-17)

3.3. ASSOCIATIONS BETWEEN DEMOGRAPHIC INDICES AND ILLNESS REPRESENTATIONS, KNOWLEDGE, ADHERENCE AND OUTCOME MEASURES.

The demographic variables of gender, severity, duration of asthma and material deprivation as objective indices were explored to consider the extent to which they were associated with illness representations, knowledge, adherence and outcome measures. There were no hypotheses related to demographic variables however they were examined to enable any significant associations to be controlled for in later analysis. Significant results are presented in table 19. A full table of results is presented in Appendix 13.

Table 19. Significant Results for Group 1 on Demographic Indices

	GROUP 1	
	Statistic	Sig (p)
Gender + Subjective distress	Kendalls Tau-C .483	.045 *
Gender + Germ/Virus	Kendalls Tau-C -.544	.026 *
Duration+ Timeline	Pearson R .473	.047 *
Deprivation+ Active quality of Life	Pearson R .521	.026 *
Deprivation + Passive quality of life	Pearson R .5526	.017 **

Significant at * p < .05; ** p < .02; *** p < .001

As shown in Table 19 significant results for Group 1 included, positive correlations between gender and subjective distress, with more girls reporting a higher subjective distress. A significant negative correlation between gender and a belief in germ/virus as causative with boys more strongly endorsing this belief. Longer duration of asthma was positively correlated with higher perceived duration of illness. Correlations with deprivation showed significant positive correlations with active and passive quality of life.

Significant results on demographic indices for Group 2 are presented in Table 20.

Table 20. Significant Results for Group 2 on Demographic Indices

	GROUP 2	
	Statistic	Sig (p)
Gender + Control/Cure	Kendalls Tau-C -.476	.018 **
Gender+ Germ/Virus	Kendalls Tau-C -.544	.003 **
Gender + Knowledge	Kendalls Tau-C .431	.040 *

Significant at * p < .05; ** p < .02; *** p < .001

As shown in Table 20, significant negative correlations were found between Gender and; Control/Cure (with boys showing higher perceptions of control/cure), and Germ/Virus as causative (with boys more strongly endorsing this belief). A significant positive correlation was found between gender and knowledge, with girls showing greater knowledge.

3.4. ASSOCIATIONS BETWEEN ILLNESS REPRESENTATIONS WITH MANAGEMENT, KNOWLEDGE, ASTHMA CONTROL AND QUALITY OF LIFE.

The correlations at univariate level between children's illness representations and adherence, knowledge, asthma control and quality of life for Group 1 and 2 are presented in Tables 21- 28.

The results of Correlations between illness representations and adherence are presented in Table 21.

Table 21. Correlations of Illness Representations with Adherence for Group 1 and 2

VARIABLE	GROUP 1			GROUP 2		
	Co-efficient (r)	Sig (p)	(D.F.)	Co-efficient (r)	Sig (p)	(D.F.)
Illness Identity	-.2997	.227	18	.1896	.386	23
Consequences	.1467	.561	18	-.0728	.741	23
Control/Cure	.1084	.668	18	-.0091	.967	23
Timeline	-.1323	.601	18	-.1019	.644	23
Pollution	.5129	.030 *	18	.2697	.213	23
Others	.2398	.338	18	-.1214	.581	23
Medical Care	.3020	.223	18	—————		
Hereditary	.0794	.754	18	.1276	.562	23
Stress/Worry	.0700	.783	18	.0562	.799	23
Emotional	.1602	.525	18	-.1821	.406	23
Food Allergy	.2584	.301	18	.0848	.701	23
Bad Luck	.0993	.695	18	-.0581	.792	23
Own Behaviour	-.2867	.332	18	-.1637	.455	23
Germ/Virus	.3614	.141	18	-.1657	.450	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 21, for the younger children adherence was positively correlated with a belief in pollution as causative. For the older children there were no significant correlations with adherence.

The results of correlations between illness representations and knowledge are presented in Table 22

Table 22. Correlations of Illness Representation with Knowledge for Group 1 & 2

VARIABLE	GROUP 1			GROUP 2		
	Co-Efficient (r)	Sig (p)	(D.F.)	Co-Efficient (r)	Sig (p)	(D.F.)
Illness Identity	-.219	.382	18	.459	.028 *	23
Consequences	.096	.705	18	.184	.399	23
Control/Cure	.098	.698	18	-.294	.173	23
Timeline	.098	.697	18	.168	.442	23
Pollution	.166	.509	18	-.236	.277	23
Others	-.126	.618	18	.225	.301	23
Medical Care	.065	.796	18	-----	-----	-----
				-	-	-
Hereditary	.007	.977	18	-.142	.517	23
Stress/Worry	-.395	.104	18	.297	.169	23
Emotional	-.514	.029 *	18	.004	.983	23
Food Reaction	-.283	.255	18	.163	.455	23
Bad Luck	-.088	.727	18	.205	.348	23
Own behaviour	-.2593	.299	18	-.160	.465	23
Germ/Virus	.177	.480	18	-.211	.332	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 22 for the younger children there was a significant negative correlation between knowledge and a belief in emotional factors as causative. For the older children there was a significant positive correlation between knowledge and illness identity.

The correlations between illness representations and asthma control are presented in Table 23.

Table 23. Correlations of Asthma Control with Illness Representations for Group 1 & 2.

VARIABLE	GROUP 1			GROUP 2		
	Co-Efficient (r)	Sig (p)	(D.F.)	Co-Efficient (r)	Sig (p)	(D.F.)
Illness Identity	.040	.873	18	.129	.556	23
Consequences	.180	.474	18	.239	.270	23
Control/Cure	.264	.288	18	.399	.059	23
Timeline	-.247	.321	18	-.314	.144	23
Pollution	.3734	.127	18	.065	.766	23
Others	-.064	.800	18	.297	.168	23
Poor Medical Care	.101	.689	18	-----	-----	-----
Hereditary	-.361	.140	18	.008	.968	23
Stress/Worry	.096	.705	18	.329	.125	23
Emotional	.048	.850	18	.477	.021 *	23
Food Reaction	.342	.165	18	-.048	.825	23
Bad Luck	-.198	.429	18	.182	.404	23
Own behaviour	.145	.565	18	.254	.241	23
Germ/Virus	-.011	.963	18	.103	.640	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As Shown in Table 23 there were no significant correlations between asthma control and illness representations for the younger children. In group 2 a significant positive correlation was found between asthma control and a belief in emotional factors as causal.

The results of correlations between active quality of life with illness representations are presented in Table 24.

Table 24. Correlations of Active Quality of Life With Illness Representations Group 1 & 2.

VARIABLE	GROUP 1			GROUP2		
	Co-efficient (r)	Sig (p)	(D.F)	Co-efficient (r)	Sig (p)	(D.F.)
Illness Identity	-.1657	.511	18	.1437	.513	23
Consequences	-.3876	.112	18	.0507	.818	23
Control/Cure	.2507	.316	18	.1035	.638	23
Timeline	-.0507	.842	18	-.1683	.443	23
Pollution	.6614	.003 **	18	.0927	.674	23
Others	.0654	.797	18	-.1689	.441	23
Medical Care	.3797	.120	18	-----		
Hereditary	.0284	.911	18	-.3608	.091	23
Stress/Worry	.2988	.228	18	-.2060	.346	23
Emotional	-.1399	.580	18	.2096	.337	23
Food Allergy	.0355	.889	18	-.0635	.773	23
Bad Luck	.2167	.388	18	.0453	.837	23
Own Behaviour	-.5947	.009 **	18	.0099	.964	23
Germ/Virus	.2665	.285	18	.3269	.128	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 24 there were significant positive correlations for the younger children between active quality of life and a belief in pollution as causative. Also a negative correlation with a belief in one's own behaviour as causative. For the older children there were no significant correlations with active quality of life.

The results of correlations between passive/teenage quality of life and illness representations are presented in Table 25.

Table 25. Correlations of Passive Quality of Life for Group 1 and Teenage Quality of Life For Group 2 With Illness Representations.

VARIABLE	GROUP 1			GROUP2		
	Co-efficient (r)	Sig (p)	(D.F)	Co-efficient (r)	Sig (p)	(D.F.)
Illness Identity	-.1027	.685	18	-.0671	.761	23
Consequences	-.1046	.680	18	-.2690	.214	23
Control/Cure	-.0428	.866	18	.3014	.162	23
Timeline	-.0224	.930	18	.1172	.594	23
Pollution	.4196	.083	18	.0133	.952	23
Others	-.0861	.734	18	-.5226	.011 **	23
Medical Care	.2126	.397	18	————		
Hereditary	-.0551	.828	18	-.0597	.787	23
Stress/Worry	.4676	.050 *	18	.2005	.359	23
Emotional	.2205	.379	18	.0593	.788	23
Food Allergy	.3188	.197	18	.2473	.255	23
Bad Luck	.2102	.402	18	.2312	.289	23
Own Behaviour	.0385	.880	18	.1270	.564	23
Germ/Virus	.0600	.813	18	.1589	.467	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 25 there were significant positive correlations for the younger children between passive quality of life and a belief in stress/worry as causative and adherence. For the older children there was a significant negative correlation between teenage quality of life and a belief in others as causative.

The results of correlations between subjective severity with illness representations are presented in Table 26.

Table 26. Correlations of Subjective Severity With Illness Representation Groups 1 and 2.

VARIABLE	GROUP 1			GROUP 2		
	Co-efficient (r)	Sig (p)	(D.F)	Co-efficient (r)	Sig (p)	(D.F.)
Illness Identity	-.0370	.884	18	.4942	.017 **	23
Consequences	.3130	.206	18	.4753	.022 *	23
Control/Cure	-.0121	.962	18	-.0761	.730	23
Timeline	.3612	.141	18	-.1594	.467	23
Pollution	.2295	.360	18	.3305	.123	23
Others	-.2979	.230	18	.2017	.356	23
Medical Care	-.3270	.185	18	-----		
Hereditary	-.2228	.374	18	.1590	.469	23
Stress/Worry	.1876	.456	18	.1291	.557	23
Emotional	.2313	.356	18	.3464	.105	23
Food Allergy	.3980	.102	18	.0930	.673	23
Bad Luck	-.1303	.606	18	-.0545	.805	23
Own behaviour	.4054	.095	18	.1044	.635	23
Germ/Virus	-.6168	.006 **	18	.2217	.309	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$.

As shown in Table 26 there was a significant negative correlation for the younger children between subjective severity and a belief in germs/virus as causative. For the older children subjective severity was positively correlated with illness identity and illness consequences.

The results of correlations between subjective distress with illness representations are presented in Table 27.

Table 27. Correlations of Subjective Distress About Asthma With Illness Representation, for Group 1 and 2.

VARIABLE	GROUP 1			GROUP2		
	Co-efficient (r)	Sig (p)	(D.F)	Co-efficient (r)	Sig (p)	(D.F.)
Illness Identity	.5455	.019 **	18	.1208	.583	23
Consequences	.4613	.054	18	.2799	.196	23
Control/Cure	.2970	.231	18	.0376	.865	23
Timeline	-.2807	.259	18	-.2449	.260	23
Pollution	-.5183	.028 *	18	.4455	.033 *	23
Others	-.1044	.680	18	.0791	.720	23
Medical Care	-.1258	.619	18	—————		
Hereditary	.1966	.434	18	-.1469	.504	23
Stress/Worry	-.3640	.137	18	-.1467	.504	23
Emotional	-.0411	.871	18	.2609	.229	23
Food Allergy	-.3810	.119	18	-.0629	.775	23
Bad Luck	-.3396	.168	18	-.1277	.562	23
Own Behaviour	.3262	.186	18	.3237	.132	23
Germ/Virus	.1854	.461	18	.0841	.703	23

Significant at * p < .05; ** p < .02; *** p < .001.

As shown in Table 27 for the younger children there was a significant positive correlation between subjective distress and illness identity and a significant negative correlation with pollution as causative. For the older children a significant positive correlation with pollution as causative was observed.

The results of correlations between reactivity with illness representations are presented in Table 28.

Table 28. Correlations of Reactivity With Illness Representations for Group 2

VARIABLE	GROUP 2		
	Co-efficient (r)	Significance (p)	(D.F.)
Illness Identity	.4263	.043 *	23
Consequences	.4172	.048 *	23
Control/Cure	-.4376	.037 *	23
Timeline	.2106	.335	23
Pollution	.0625	.777	23
Others	-.1139	.605	23
Medical Care	-----	-----	-----
Hereditary	-.1540	.483	23
Stress/Worry	.0255	.908	23
Emotional	-.1014	.645	23
Food Allergy	.0043	.984	23
Bad Luck	-.1829	.403	23
Own Behaviour	-.0879	.690	23
Germ/Virus	-.2209	.311	23

Significant at * $p < .05$; ** $p < .02$; *** $p < .001$

As shown in Table 28 there were significant positive correlations between reactivity and; illness identity, illness consequences as well as significant negative correlation with control/cure.

3.5. ASSOCIATIONS BETWEEN KNOWLEDGE AND ADHERENCE, ASTHMA CONTROL AND QUALITY OF LIFE.

The results of correlations between knowledge with adherence, asthma control and quality of life are presented in Table 29.

Table 29. Correlations between knowledge and adherence, asthma control and Quality of Life

	GROUP 1			GROUP 2		
Variable	Co-Efficient (r)	Sig (p)	(D.F.)	Co-Efficient (r)	Sig (p)	(D.F.)
Adherence	.096	.704	18	.278	.198	23
Asthma control	.181	.471	18	.095	.665	23
Active Quality of Life	-.060	.813	18	-.187	.339	23
Passive/Teenage Quality of Life	-.494	.037 *	18	-.108	.623	23
Subjective severity	-.079	.754	18	.091	.678	23
Subjective distress	-.091	.718	18	-.377	.075	23
Reactivity	-----	-----	-----	.050	.820	23

Significant at * p < .05; ** p < .02; *** p < .001

As shown in Table 29 for the younger children there was a significant negative correlation between knowledge and passive quality of life. No significant associations were found for the older group.

3.6. ASSOCIATIONS BETWEEN ADHERENCE AND ASTHMA CONTROL AND QUALITY OF LIFE.

The results of correlations between adherence and asthma control and quality of life are presented in Table 30.

Table 30. Correlations between Adherence and Asthma Control and Quality of Life.

Variable	GROUP 1			GROUP 2		
	Co-Efficient (r)	Sig (p)	(D.F.)	Co-Efficient (r)	Sig (p)	(D.F.)
Asthma Control	.280	.259	18	-.369	.083	23
Active Quality of Life	.580	.012 **	18	.180	.411	23
Passive/Teenage Quality of Life	.478	.045 *	18	-.088	.687	23
Subjective severity	-.253	.310	18	-.127	.563	23
Subjective distress	-.305	.218	18	.127	.561	23
Reactivity	-----	-----	-----	.050	.820	23

Significant at * p < .05; ** p < .02; *** p < .001

As shown in Table 30 for the younger children there were significant positive correlations between adherence and active and passive quality of life. No significant associations were found for the older children.

3.7. RELATIVE CONTRIBUTIONS OF DEMOGRAPHIC INDICES, ILLNESS REPRESENTATIONS, KNOWLEDGE AND ADHERENCE TO ASTHMA CONTROL AND QUALITY OF LIFE.

The measures which were significantly correlated with each of the outcome measures, at univariate level, were entered into a series of hierarchical multiple regression analysis to determine their relative contributions to asthma control and quality of life measures. Significant demographic variables, when present, at univariate level were entered into each regression first to control for these factors. The remaining variables were entered into the regression in blocks with illness representations entered second and then adherence and/ or knowledge. Results are presented separately for each group in Table 31 and Table 32.

Table 31. Relative Contributions of Demographic Indices, Illness Representations, Adherence and Knowledge with Asthma Control and Quality of Life measures for Group 1.

Dependent Variable	Independent Variable	¹ %	B Value	β	P
Active Quality of Life	Deprivation	22	.698	-.319	.055
	Pollution	25	.319	-.359	.033 *
	Poor Self Care	14	1.67	.544	.026 *
	Adherence	0	.544	.118	.560
	Adjusted R ² = .61 F=.002 **				
Passive Quality of Life	Deprivation	26	.498	.442	.021 *
	Stress/Worry	10	.363	.197	.281
	Knowledge	15	-.341	-.405	.036 *
	Adherence	7	.701	.296	.095
	Adjusted R ² = .58 F=.003 **		.340	.185	.107
Subjective Severity	Germ/Virus	34	-1.78	-.616	.006 **
	Adjusted R ² = .34 F=.006 **				
Subjective Distress	Gender	18	2.89	.266	.223
	Illness Identity	9	-2.52	-.428	.036 *
	pollution	16	.306	.338	.132
	Adjusted R ² = .43 F=.011 **				

¹ % Variance derived from adjusted R square. Significant at * p < .05; ** p < .01; *** p < .001.

As Shown in Table 31 on measures of active quality of life, 61 per cent of variance was explained by deprivation, pollution, poor self-care and adherence. Illness representations with a belief in pollution and poor self-care as causal made significant independent contributions to the proportion of variance explained (p= .033, p=.026) respectively, adherence did not add to the amount of variance explained. The beta values show that illness representations explained a greater proportion of variance than other variables.

On passive quality of life overall 58 per cent of the variance was explained by deprivation, stress/worry, knowledge and adherence. Deprivation and knowledge made significant independent contribution (p=.021, p=.036) respectively. Deprivation explained the greater proportion of variance.

With subjective severity 34 per cent of the variance was explained by a belief in germs/virus as causal ($p=.006$). On the measure of subjective distress overall 43 percent of the variance was explained by gender, pollution and illness identity. A belief in pollution as causal made a significant independent contribution ($p=.036$). A greater proportion of variance was explained by illness representations than gender.

The results for Group 2 are presented in Table 32.

Table 32. Relative Contributions of Demographic Variables, Illness Representations, Adherence and Knowledge with Asthma Control and Quality of Life measures for Group2

Dependent Variable	Independent Variable	¹ %	B Value	β	P
Asthma Control	Emotional	19	.911	.477	.021 *
	Adjusted R ² .19				
	F= .021 *				
Active Quality of Life	Gender	47	-5.33	-.705	.000 ***
	Adjusted R ² .47				
	F= .000 ***				
Teenage Quality of Life	Others		-1.68	-.522	.010 **
	Adjusted R ² = .23				
	F= .010 **				
Subjective Severity	Illness Identity	20	.277	.362	.083
	Consequences	6	1.30	.330	.118
	Adjusted R ² = .26				
	F=.016 **				
Subjective Distress	Gender	10	-4.81	-.268	.202
	Pollution	8	2.90	.355	.096
	Adjusted R ² = .18				
	F=.047 *				
Reactivity	Illness Identity	14	.206	.222	.289
	Consequences	3	1.39	.291	.159
	Control/Cure	10	-2.23	-.351	.077
	Adjusted R ² = .27				
	F= .029 *				

¹ % Variance derived from adjusted R squared. Significant at * $p < .05$; ** $p < .01$; *** $p < .001$.

As shown in Table 32 the results of the multiple regression for Group 2 indicate that on asthma control a belief in emotional factors as causal explained 19 per cent of the variance which was significant at ($p=.021$).

On measures of quality of life 59 per cent of the variance of active quality of life was explained by: deprivation, pollution and poor self-care as causal and adherence. Significant independent contributions were made by deprivation ($p=.005$), pollution ($p=.003$) and poor self-care ($p=.026$). By examination of the beta weights illness representations explained a greater proportion of the variance in the regression equation.

On passive quality of life 58 per cent of the variance was explained by deprivation, stress/worry as causal, knowledge and adherence. Significant independent contributions were made by deprivation ($p=.021$) and knowledge ($p=.036$). Knowledge, deprivation and adherence explained a greater proportion of the variance than illness representations.

On subjective severity 34 per cent of the variance was explained by a belief in Germ/Virus as causal ($p=.006$). With subjective distress 43 per cent of the variance was explained by gender, pollution and Illness Identity. A belief in pollution as causal made a significant independent contribution ($p=.036$). Overall illness representation explained a greater proportion of the variance as shown by the beta weights than gender.

4. DISCUSSION

4.1. Discussion Of Method

The response rate of 27.6 per cent is not atypical in this type of design although the ethical difficulty of accessing children may have lowered the rate of response. In addition the sample was obtained from GP practices and as such included predominately children with mild to moderate asthma. Recruitment from paediatric clinics would have enabled children with more severe and uncontrolled asthma to be included.

The issue of reliability of measures was a major consideration in the study. Using measures that were well standardised was not possible given the research questions and the paucity of available measures that have been specifically developed for children. This necessitated developing or adapting existing measures. The discussion of method will consider; the general issues relative to reliability, the specific measures used and their performance in this study and statistical issues.

General issues related to measurement

A major difficulty was the low internal consistency and variable test-retest reliability of some of the measures. Low internal reliability may, in part, be explained in terms of scale construction. Many standardised measures include reversal items which are ways of asking a question in a similar way. This method has the effect of increasing the

inter-correlations between items and thus increasing the scale's internal consistency. During the pilot study reversal questions on the IPQ were found to be confusing to children and were therefore not included. Reversal questions were similarly avoided in the management scale in view of this. This may have contributed to the lower reliability of some scales.

With regard to stability over time, the fact that only a small sample of children from each group were tested at time two may influence the results and a larger test-retest sample would have been more robust. The older children consistently showed lower test-retest correlations across measures. It may be possible that the measures were not reliable due to poor test construction, however, the fact that measures were more consistent for the younger children would suggest that it was not due specifically to this. An alternative explanation is that the results may accurately reflect that, for adolescents, the perceptions and behaviour under study are inherently variable. This issue will be developed further in the general discussion.

Specific measures

The IPQ was adapted from the adult version and internal reliability was found to be slightly lower on some scales than found in previous research with adults. The measure appeared to demonstrate good test-retest consistency for the younger children but not for the older ones. In the pilot study some support was found for the content of the cause questions as children's spontaneously endorsed certain beliefs

although not all. Thus a possible demand characteristic may have resulted from the cause questions shaping children's responses. The adult version had been developed empirically. To check on the validity of constructs, in depth qualitative methods using semi-structured interviews could be utilised to access childrens' beliefs across the age ranges.

The change in administration of the knowledge measure improved its reliability for the older children but reduced it for the younger group. At re-test the measure was consistent for young children but not for the older children. On examination the older children showed greater knowledge at time two. Since no feedback was given on the errors children made, it is possible that the measure had an intervention effect and knowledge improved between testing due to the interview making asthma information salient. The younger children were less knowledgeable than the older group and have less experience to draw on. This may have resulted in more inconsistency. The added "don't know" response, may have allowed this uncertainty to be expressed rather than guessing, thus reducing the measure's reliability.

The management measure was drawn from an analysis of core competencies by Mc Nabb et al (1986). The separation of specific preventative, intervention and compensatory behaviours has not found psychometric support in this study. The dimensions eventually constructed by factor analysis, with the exception of adherence, similarly had little psychometric support. It is probable that asthma management is

variable, partly due to the episodic nature of asthma, which would not be measured in a cross-sectional design. The fact that greater consistency was observed with the younger group may reflect that parental influence on management is greater in the younger children.

The results on the asthma control measure would suggest that, on the whole, the sample included children whose asthma was well controlled. However, upwards of thirty per cent of the children had, due to their asthma, lost days from school, disturbed their parents at night or visited their GP in the two months prior to interview. This may suggest that the measure was not sensitive enough to access the fluctuations of asthmatic symptoms. Alternative methods, such as measuring lung function, were considered and rejected because a single measurement would be inadequate and repeated measurement of lung function would represent an intervention by its potential to alter perceptions of asthma.

A further consideration is that the asthma control measure represented parental reports. Clearly whether a child stays at home or visits the GP would be based on parental perceptions of their child's symptom severity. As discussed in the introduction parental perceptions often differ from others' perceptions or objective indices.

The quality of life measures performed well and consistencies were found between this sample and those on which the measures had been standardised. It was easily

understood by children and the response format for the younger children appeared to be enjoyed. The lack of comparability between the two scales did not allow for comparisons between the age groups.

Statistical issues.

In view of the exploratory nature of the study it was decided to set a less stringent significance level at $\alpha < 0.05$. This was to achieve a balance between obtaining Type 1 and Type 11 errors. Due to the large numbers of tests performed, the less stringent significance level may have resulted in Type 1 errors. A more stringent significance may have resulted in Type 11 errors for a number of reasons. The low reliability of the measures may have reduce their sensitivity to detect significant differences and associations. In addition the sample were comprised of relatively well controlled, knowledgeable and adherent children, and lack of sensitivity of measures, particularly asthma control, may have reduced the chance of finding significant results at a less stringent level. The data yielded by many of the measures particularly the IPQ and adherence give a relatively small range. Therefore, large effect sizes would be required to detect significant results.

In the multiple regression analysis, only variables that were significant at univariate level were entered. Other variables that were not significant at univariate level may have become so at multivariate level. Due to the small sample size within each group it was not possible to permit regression analysis employing all the variables. The fact

that in some of the analysis the variables did not by themselves show significant contributions may suggest that there was either shared variance with other variables or that other factors other than those entered were more important predictors of outcome.

4.2. General Discussion

Aims and Hypotheses

The purpose of the study was to explore the content of illness representations using the IPQ in children aged between 8-11 years and 12-16 years, and to examine differences and relationships between illness representations, knowledge, management, asthma control and quality of life. Six hypotheses were generated, and the discussion will focus on the main findings related to these.

1: Age groups will differ on measures of a) illness representations b) knowledge c) management.

There were no significant differences between the groups on the subscales of the IPQ suggesting that children across the age range had similar perceptions of the consequences, duration and controllability/curability of their asthma. Perceived duration of asthma was moderate which is counter to Eiser et al (1989) who found children in their sample believed their asthma was of short duration.

No children endorsed being naughty as a possible cause of their asthma which would suggest that children were not offering explanations of causes that were at an earlier developmental level than expected for their age, as had been suggested by Berry et al. (1991). Younger children, however, more strongly endorsed external causes such as a germ/virus explanation and a belief in poor past medical care. However, similar to Eiser et al (1989), children in both age groups more strongly endorsed hereditary factors and then pollution as causative. This may indicate that younger children have some strong beliefs about the role of germs and viruses but are beginning to incorporate more complex conceptualisations, in line with work by Burbach & Peterson (1986). Bishop & Converse (1986) found that individuals process illness-relevant information according to prototypic schema. It is possible that younger childrens' asthma related schemata are less developed due to less experience with asthma as suggested by Carey (1985). The large range of the age bands, particularly in the older group may, however, have obscured age differences.

The children in both groups demonstrated a higher level of knowledge compared to previous research by Eiser et al (1989) and Parcel et al (1980), which would suggest that this was a relatively knowledgeable group of children. This may be the result of excluding children with low verbal ability. Unlike the findings of Eiser et al (1989) there were age differences, with the older children being more knowledgeable.

On the whole the sample was comprised of adherent children. Although the older children were less adherent, as suggested by Christiaanse (1989), this was not found to be a significant result. Similar to the work of Smith et al (1986) and Weinstein and Cuskey (1985) no demographic indices were associated with adherence. A more diverse sample of asthmatic children may have shown a different pattern and the wide age band in the older group may have obscured age differences. The possibility that children were overly reporting adherent behaviour may also be a consideration, although the method attempted to minimise this reporting bias.

2: Illness representations will be related to a) Knowledge b) management c) asthma control d) quality of life.

Knowledge was found to be associated with older children's labelling of asthma symptoms as greater knowledge was associated with a higher illness identity. For the younger children higher levels of knowledge were associated with less endorsement of emotional factors as causative, which suggests that knowledge has some role in shaping children's beliefs. Lack of other associations for the younger children may reflect their relative inexperience and greater uncertainty with regard to their knowledge of asthma. The lack of associations between knowledge and children's perceptions of the consequences, control/cure or timeline of their asthma would suggest that formal knowledge appears to be less integrated into the individual's illness related schema as suggested by the self-regulation model.

For younger children better adherence was associated with a belief in pollution as causative. This may reflect that pollution is considered to be a threat that guides younger children's behaviour. There were no associations between illness representations and adherence for the older children, suggesting that adherence in this age group is related to other factors. The finding that perceptions of control/cure did not appear to be related to adherence is surprising since work with adults has shown such associations (Weinman et al 1995). An alternative and more recent conceptualisation is suggested by Horne (in press). Horne (in press) has found that cognitions related to beliefs about treatment guide adherence rather than a purely illness-oriented representation of beliefs about control/cure. These treatment perceptions relate to how effective individuals' believe medication to be, and how medication side effects are perceived. This would be an important consideration for future research with children and their parents. The instability of perceptions of control/cure in the older children may also be due to the unpredictable nature of asthma. Non-adherence may, at times, have no adverse effect but at other times, despite best adherence efforts, a child may be symptomatic. This may represent contrary evidence on which a child has to base their beliefs about treatment efficacy and the lack of associations may be influenced by this.

For the older children, lower asthma control was associated with a stronger endorsement of emotional factors as causal. Emotional factors, such as anxiety, are known to interact with asthma and exacerbate symptoms although it is not possible to

state the direction. There were no associations for the younger group between illness representations and asthma control. This may be due to the insensitivity of the measure, based on parental perceptions, and objective indices of asthma (e.g. lung function) may have shown associations. The sample were, on the whole, well controlled, and perceptions of consequence and control/cure may be very different when children are symptomatic. In a fluctuating disease, such as asthma, longitudinal research, using repeated measures, would enable perceptions to be tracked over time.

The mean scores suggest that the sample, on the whole, had a moderate to high perceived quality of life and few associations were found between illness representations and quality of daily living. However daily quality of life, is less likely to be affected in children with mild asthma (Christie et al., 1993), and this sample included predominately mild to moderate asthmatic children. With the younger group, however, higher perceptions of active quality of life were associated with stronger endorsements of a belief in pollution as causal and lower perceptions with a belief in ones own behaviour as causal. Brewer (1982) suggested that certain beliefs in younger children are associated with lower perceptions of personal responsibility. External causes, such as pollution, that are outside the child's control may have less influence on a child's perceptions of daily living than internal causes such as a belief in ones own behaviour as responsible. For the older children, however, there was a different pattern and lower endorsement of others as responsible for their asthma was associated with a higher perceived teenage quality of life which may suggest that self-

efficacy has a role in daily quality of life. This finding has been noted in research into disability with greater perceptions of control and self-efficacy being predictive of greater recovery of function (Johnson, 1996).

Younger children who more strongly endorsed a germ/virus explanation were found to have lower perceptions of asthma severity, which may suggest a protective function of external causal beliefs. The fact that other illness representations did not appear to be significantly associated, however, may indicate that for younger children perceptions of severity may be based more on the extent to which asthma restricts their daily lives. This would concur with the findings of Christie et al (1993) that subjective severity tends to be associated with more objective indices such as lung function. For older children, however, a higher perception of asthma as having serious consequences and a greater illness identity was associated with greater perceptions of severity. This would seem to be consistent with the findings in the adult literature and may indicate that the older children were making more sophisticated links between illness perceptions and perceptions of severity.

The distress that children reported showed clear differences between the age groups. For the younger group, greater symptom perception was associated with greater distress about their asthma. It was surprising that this association was not found in the older children. Perceived distress was moderate to high for the younger children and moderate for older children. The lack of comparability between the scales did not

permit possible differences between perceptions of distress to be considered. For the younger group distress was lower if pollution was more strongly endorsed as a causal factor. This pattern was reversed for the older children with higher perceptions of distress being associated with beliefs in pollution as causal. This rather mixed result may be explained in developmental terms in that the consequences of pollution are understood and influence children in different ways. Christie et al (1993) suggested that subjective quality of life is more closely related to how children feel than how symptomatic they are. Although subjective quality of life was not measured against objective indices. How symptomatic a child perceived themselves as being was related to perceived distress for younger children. This would suggest that illness perceptions could play an important role in well-being.

The lack of relationships between perceptions of consequence and control/cure with subjective distress are surprising. However, this may be due to the moderate to high perceptions of control/cure and low perceived consequences in this sample.

For older children, associations were found between several attributes of the IPQ and higher levels of reactivity such as; a higher illness identity, greater perceptions of asthma having serious consequences and a lower perceptions of control and curability. Reactivity questions related to how children and their perceptions of asthma interact with their daily environment and how these perceptions may shape their attitudes to issues such as smoking. This represents an interesting finding and suggest that illness

representations may have a wider influence than illness related behaviour and outcome, for this age group. There is, therefore, a potential for future research in considering how illness representations influence teenagers decisions about smoking.

3: Knowledge will not be related to a) management b) asthma control c) quality of life.

Knowledge was not associated with adherence or asthma control for either group. This would support the findings of Rubin et al (1989), and suggests the role of knowledge in management may not to be direct. Although the knowledge measure was unreliable for the younger group, associations were not evident for the older group with whom reliability was good. This finding would also suggests that the concrete and somatic aspects of illness may be more influential in guiding action than the abstract or formal knowledge that an individual holds, as proposed by self-regulation theory. However, it is also possible that this may represent a ceiling effect given the levels of knowledge, adherence and asthma control in this sample.

4: Good self-management will be associated with better a) asthma control b) higher perceived quality of life.

No associations were found between adherence and asthma control. This may also reflect a ceiling effect or insensitivity of measures. An alternative possibility is that the

relationship is not linear and children's perceptions may mediate between management and outcome as suggested by the self-regulation model.

For the younger children better adherence was associated with higher perceptions of active and passive quality of life which may be reflecting a link between symptom control and higher perceptions of daily quality of life in young children, as suggested by Christie et al. (1994). Perceptions of severity and distress tend to be more independent of symptom control, which was found in the lack of association, for young children between subjective perceptions of severity and distress and adherence. No relationships were found between adherence and quality of life for the older group, which may indicate that more external factors are influential for older children. The high levels of adherence and control may be influencing these results although a consideration, when assessing management in an episodic condition, is there may be a time lag between symptoms and management efforts. As suggested above illness representations may mediate these relationships.

Hypothesis 5 and 6 will be discussed together.

5: Illness representations will be more strongly related than knowledge to asthma control and quality of life.

6: Illness representations will be more strongly related than management to a) asthma control and b) quality of life.

For the younger group, no variables were associated with asthma control at univariate level and, therefore, this hypothesis was not tested. With active quality of life illness representations explained more of the variance than adherence, whilst knowledge was not significant at univariate level and, therefore, not entered. On passive quality of life, material deprivation and knowledge made significant independent contributions and explained a greater percentage of the variance than illness representations. On subjective severity and distress, illness representations explained a significant proportion of the variance but knowledge and adherence were not significant at univariate level and not entered.

For the older group, illness representations explained significant proportions of variance on asthma control, teenage quality of life, subjective distress and reactivity, although knowledge and adherence were not significant at univariate level and not entered. Few variables were entered into the regression equation on subjective severity and distress and illness representations did not by themselves make a significant contribution. Other factors that were not tested may be more predictive for these outcome measures. Gender was found to be an important predictor of active quality of life, although no other variables were tested.

These mixed findings may reflect that the small sample size restricted the number of variables that were entered into the regression analysis. However illness representations appeared to make more of a contribution to some outcome measures than knowledge or adherence. The lack of association between illness representations and adherence runs counter to the self-regulation model. However, a similar finding is reported in the adult research which suggests that illness representations may have a direct effect on outcome (Moss-Morris et al, 1996, Schembri Wismayer, 1995). These results show some support for the self-regulatory function of illness representations although methodological factors and the complexity of results across groups limit the confidence with which inferences can be made.

Theoretical implications

Illness representations in children are different to adults perceptions and the IPQ does not perform in the same way. This was evident in the lack of association between the different components of illness representations, which show logical relationships in adult studies. In this study, only one such relationship was observed for the older children with a negative relationship between timeline and a belief in controllability and curability. It is possible that, in children, these relationships are more complex and perceptions more variable.

Although illness representations were similar across groups, how they influenced outcome showed marked variation between groups. For the younger children, with

few exceptions, unitary beliefs about cause appeared to be more strongly related to outcome measures than the constellations of perceptions about the consequences, controllability /curability and duration of their asthma. This was not so marked for the older children for whom these factors made a greater contribution to outcome. This would suggest that young children's causal attributions may be an important influence on how they perceive the quality of their life. The results for older children suggest they are beginning to approximate adult patterns of holding a set of related belief that influence behaviour and outcome. The inconsistency demonstrated suggests that these beliefs are, as yet, unstable and will fluctuate.

Overall there was some support for the self-regulation model. Illness perceptions were related to outcome, although links between perceptions and behaviour related to illness, (such as adherence), were not found. The variability of these illness representations and the clear differences between groups, although complex, shows some patterns that may be considered to be developmentally determined.

The variability in results and reliability of measures may also be influenced by development. The low internal and test-retest reliability measures and instability over time with the older group suggests that younger children are more consistent. Although problems with measures may have contributed to this, it represented a stable pattern across measures. A possible reason for this greater consistency in the younger children is that perceptions are more stable because self-management behaviour and

thus asthma control may be more influenced by parental factors. Problems with adjustment and adherence with chronic illness during adolescence are well documented (Eiser, 1993). Inconsistencies can be considered developmentally appropriate for the older group and other factors, such as peer pressure and social acceptance, may be as or at times more influential guides to management and outcome than parental influence or individual illness perceptions. A further consideration would be the affect of mood swings in adolescence. This may have the effect of making self-management more variable and also the noted affect of mood on asthma and cognitions may, in part, contribute to the variability of older children's perceptions at time two.

There were gender differences in children's perceptions and response to asthma. Girls in the younger group reported a higher level of distress, unrelated to disease severity. Although this was not found in the older group it may reflect, for younger children, known effects of gender role socialisation with girls reporting more distress than boys and boys perhaps minimising the consequences of their asthma. In addition, boys in both groups more strongly endorsed a germ/virus cause which may be due to gender differences in cognitive development. Although there were no gender differences noted on perceptions of consequences of asthma, in the older group, girls had lower perceptions of control/cure which would suggest that girls may be more vulnerable to the negative aspects of asthma and this may link with lower self-efficacy (Johnson, 1996). Clearly more exploration is needed to clarify these relationships

although they could have important implications when assessing and intervening with asthmatic children.

4.3. Implications for future research

This study represents an exploratory investigation into children's perceptions of asthma and clearly methodological difficulties have compounded the complexity of findings. Using the IPQ with children requires further research using qualitative methods to ensure as wide a range of beliefs that children may hold as possible to be incorporated.

The developmental patterns that were emerging from this study may be addressed in a number of ways. As mentioned the two age groups, particularly the older group, were comprised of a developmentally wide range. Future research would need to employ a bigger sample so that the age groups may be further divided and include younger children to track the developmental nature of illness representations.

Asthma is an episodic condition and a cross sectional study reduces the confidence in stability of measures and perceptions. A longitudinal design would enable perceptions to be tracked over time. In addition, the IPQ subscale of timeline is perhaps biased toward more stable conditions. Adapting the scale for illnesses with a more fluctuating time course would enable greater sensitivity.

In view of more recent developments in illness perceptions (Horne, in press), an important area for future research would be to explore perceptions related to treatment and management to enable further understanding of the barriers to good self-management for children of different ages.

The close association between the reactivity measure and illness representations would suggest that illness representations may have a wider impact on the interaction between children's asthma and their social environment. The potential to consider their role in relation to smoking represents a potential area for future research.

This study aimed to look at what children's illness representations are, future research should now consider how they develop. Clearly the parents' perceptions are important and particularly so for younger children. During adolescence when greater autonomy is developing other influences will become more important and management may be influenced by the degree to which parental and child illness representations mesh. A lack of concordance in later childhood may be an important factor in adolescents responses to illness and self-management. There would appear to be a clear need to integrate other models of understanding to encapsulate the variety of factors that influence children, parents and their behaviour by using a multi-theoretical framework.

4.4. Implications for Clinical Practice

The IPQ, if adapted to increase its reliability and validity, may provide a useful tool for health professionals to assess and intervene in asthma and other paediatric conditions.

The results of this study, although tentative, would suggest that there is a need to take account of children's perceptions when designing and communicating self-management programs to children. Clear developmental differences in how children's perceptions influence outcome have been suggested. For younger children causal beliefs appear to be quite powerful in how a child perceives their asthma, which would need to be taken account during any intervention. The role of parents at this age would suggest the need not only to involve parents in interventions but also to assess the degree to which parental and child perceptions mesh. This may be an important factor in the success or failure of self management. For older children, perceptions and behaviour are more inconsistent and possibly more influenced by social and environmental concerns. This would suggest a need for approaches to raise awareness and improve attitudes in this age group generally, possible by school and community interventions.

Clinical psychologists are in a unique position because of the developmental and multi-theoretical perspective that informs their practice, to work with children, their families

and the wider systems that support them. Knowing how a child cognitively represents their illness adds another level to our understanding of a widespread, but poorly controlled health problem.

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APPENDIX 1

ETHICAL APPROVAL



SOUTH EAST KENT RESEARCH ETHICS COMMITTEE

Please reply to: Gerald Bassett, Committee Administrator

Our ref: 425/11/95

David Salomons Estate
Broomhill Road
Southborough
Tunbridge Wells
Kent TN3 0TG

30 January 1996

Dear

Re: The influence of children's illness representation on management morbidity and their perceived quality of life with asthma.

Thank you for your letter dated 11 January. As your letter addresses the concerns raised by the Research Ethics Committee at its meeting held on 5 January 1996, I am happy to confirm approval of the proposed study detailed at the head of this letter. However, it should be noted that this letter only gives **ethical approval** for this study and it is your responsibility to seek management approval if you have not already done so, and of any other relevant NHS body that may be involved before the project takes place.

The Committee wishes to hear of the progress and outcome of the study. The LREC wishes to be advised in advance of any significant proposed deviations from the original protocol and would expect to be informed of any unusual or unexpected results which raise questions about the safety of the research.

Thank you for submitting this study for ethical approval.

Yours sincerely

Mr L W Headley
Chairman of the Local Research Ethics Committee

APPENDIX 2

LETTER FROM GP TO PARENTS

Dear

There is currently some research taking place in this region on childhood asthma. I have agreed to contact parents of children aged between 8-16 years with asthma on my list, to ask if they would be willing to participate in this research.

The researcher aims to talk to children about their understanding and experience of asthma. The interview with your child would not last more than one hour and is structured not to be demanding. The research would require a parent to fill in some short questions about their child's asthma. It is hoped that the results would provide a greater knowledge of the factors that contribute to children's adjustment and self management and how to help children manage their asthma successfully.

Ethical approval has been granted for this research by the South Kent Local Ethics Committee. All information will be treated confidentially and names and other identifying information will not be used in the research data. Participation is voluntary and your decision to participate or not will not in any way affect the treatment you receive or may receive from the professionals who look after you and your child.

If you and your child with asthma are willing to take part in the research please complete the attached form and send it to the researcher in the pre-paid envelop as soon as possible. You will then be contacted to arrange a convenient time to meet.

If you have any further questions about this research you may contact me or the researcher --
-----who can be contacted at,

Psychology Department
Salomons Centre
Broomhill Road
Tunbridge Wells
Kent, Tel No: 01892 515152

Thank you for your co-operation,

Yours sincerely

Drs

APPENDIX 3

ILLNESS PERCEPTIONS QUESTIONNAIRE (IPQ)

IPQ

There are no right or wrong answers just answer what is most like you

How often do you feel? please tick the box that is like you

	Always	quite a lot	a little bit	Never
Pain in Chest				
Feeling sick				
Hard to breathe				
Tired				
Sore head				
Upset tummy				
Cant sleep				
Dizzy/Giddy				
Coughing				
Wheezy				
Butterflies in chest				
feeling shaky				
Can't think straight				
Dry mouth				

Put a tick in the box that is how you feel about your asthma

1: Do you think that bad air caused your asthma?

Definitely yes ☐ perhaps yes ☐ not sure ☐ perhaps no ☐ definitely no ☐

2: Does your asthma stop you doing the things your friends do?

Definitely yes ☐ perhaps yes ☐ not sure ☐ perhaps no ☐ definitely no ☐

3: Do you think that if your asthma gets bad or better is all about luck?

Definitely yes ☐ perhaps yes ☐ not sure ☐ perhaps no ☐ definitely no ☐

4: Do you think of yourself as different because you have asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

5: Do you think your asthma will get better soon?

Definitely yes perhaps yes not sure perhaps no definitely no

6: Is asthma a serious thing to have?

Definitely yes perhaps yes not sure perhaps no definitely no

7: Do you think that its someone elses fault that you have asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

8: Do you think that you got asthma because your doctor did not look after you well.

Definitely yes perhaps yes not sure perhaps no definitely no

9: Is your asthma a problem for you?

Definitely yes perhaps yes not sure perhaps no definitely no

10: Do you think that getting asthma happens in your family?

Definitely yes perhaps yes not sure perhaps no definitely no

11: Do you think there are things you can do to help your asthma

Definitely yes perhaps yes not sure perhaps no definitely no

12: Do you think you got asthma because you worried alot about things?

Definitely yes perhaps yes not sure perhaps no definitely no

13: Is your asthma getting easier to live with?

Definitely yes perhaps yes not sure perhaps no definitely no

14: Do you think your asthma will go away and then come back again?

Definitely yes perhaps yes not sure perhaps no definitely no

15: Do you think there are things you can do to help yourself when you feel wheezy and its difficult to breathe?

Definitely yes perhaps yes not sure perhaps no definitely no

16: Do you think you got asthma because you felt very sad about things?

Definitely yes perhaps yes not sure perhaps no definitely no

17: Do you think that some types of food made you have asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

18: Do you think that being naughty caused your asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

19: Do you think your asthma will get better when you are older?

Definitely yes perhaps yes not sure perhaps no definitely no

20: Do you think that the medicines will make your asthma go away?

Definitely yes perhaps yes not sure perhaps no definitely no

21: Do you think you got asthma because of bad luck?

Definitely yes perhaps yes not sure perhaps no definitely no

22: Do you think you got asthma because you did not look after yourself?

Definitely yes perhaps yes not sure perhaps no definitely no

23: Do you think you will always have asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

24: Do you think that you caught asthma from a germ?

Definitely yes perhaps yes not sure perhaps no definitely no

25: Do other people treat you differently because of your asthma?

Definitely yes perhaps yes not sure perhaps no definitely no

APPENDIX 4

PARCEL KNOWLEDGE QUESTIONNAIRE

PARCEL KNOWLEDGE OF ASTHMA QUESTIONNAIRE

IF YOU HAVE ASTHMA:

	TRUE	FALSE	?
You are always sick			
Your body parts for breathing sometimes do not work			
You should not talk about your feelings such as being afraid angry or worried			

ASTHMA ATTACKS CAN HAPPEN BECAUSE:

	TRUE	FALSE	?
You can be allergic to things like dust, pollen or animals			
You breathe things like paint fumes, petrol, smoke or pollution			

DOING SOMETHING TO KEEP ASTHMA ATTACKS FROM HAPPENING:

	TRUE	FALSE	?
Is not possible			
Might be possible by staying away from things that cause attacks			
Is something only a doctor can do something about			

TAKING ASTHMA MEDICINE FOR WHEEZING:

	TRUE	FALSE	?
Can be used to stop an asthma attack from happening			
Can be used to stop an asthma attack after it starts			
Is something children can learn to do to help themselves			
Is to relax the tightness in the tiny air tubes			

IF YOU START TO HAVE AS ASTHMA ATTACK:

	TRUE	FALSE	?
You might notice coughing before wheezing starts			
You might notice a tight feeling in your chest before wheezing starts			
You should only take your medicine after you start wheezing			

WHEN YOU HAVE AN ASTHMA ATTACK:

	TRUE	FALSE	?
You can do nothing to try to stop the attack			
Your parents must rush you to the hospital before doing anything else			
You can relax by doing breathing exercises			
You should try not to pay attention to wheezing and hope it will go away			
You should drinks lots of drinks like water			

APPENDIX 5

**BRITISH PICTURE VOCABULARY SCALE
(SHORT FORM)**

Administering the Training Items

For most subjects under the age of 8:

Use plates A, B, C and D. Administer as many training item series as necessary to secure four consecutive correct responses.

For most subjects aged 8 and over:

Use plates C, D, E and F. Administer as many training item series as necessary to secure four consecutive correct responses.

Practice Words and Keys

Training Plate	Initial Series	First Alternative Series	Second Alternative Series	Third Alternative Series
A	dog (3)	baby (2)	bed (1)	knife (4)
B	man (2)	comb (3)	fork (4)	mouth (1)
C	swing (3)	drink (4)	climb (2)	walk (1)
D	sleep (2)	eat (1)	cry (4)	crawl (3)
E	wheel (4)	zip (2)	rope (1)	rake (3)
F	mopping (1)	cycling (2)	sawing (4)	mowing (3)

(Complete directions are given in Part 1 of the Manual.)

Administering the Test Items

Basal: Highest 6 consecutive correct responses.

Ceiling: Lowest 6 consecutive responses containing 4 errors.

Starting Point: For a subject assumed to be of average ability, find the person's age indicated in the margin, and begin the test with that item. Otherwise consult Part 1 of the Manual for further instructions.

Recording Responses and Errors:

Record the subject's response (1, 2, 3, or 4) for each item administered. For each error draw an oblique line through the symbol on the right of the item as illustrated below:

17 pulley . . . (4) 3 /

(Complete directions are given in Part 1 of the Manual.)

Plate No.

Word

Key Response Errors*

2-6	1	bucket	(1)	_____	○
	2	ball	(4)	_____	△
	3	car	(2)	_____	☆
	4	wooden	(2)	_____	8
7-9	5	camera	(4)	_____	+
	6	envelope	(2)	_____	○
	7	circle	(4)	_____	△
	8	furniture	(3)	_____	☆
	9	nostril	(1)	_____	8
10-13	10	dangerous	(2)	_____	+
	11	furious	(1)	_____	○
	12	athlete	(3)	_____	△
	13	artist	(3)	_____	☆
14-18	14	weary	(3)	_____	8
	15	socket	(1)	_____	+
	16	antler	(3)	_____	○
	17	pulley	(4)	_____	△
	18	inflated	(3)	_____	☆
	19	assisting	(1)	_____	8
	20	collision	(4)	_____	+
	21	floral	(1)	_____	○
	22	goblet	(3)	_____	△
	23	utensil	(2)	_____	☆
	24	talon	(3)	_____	8
	25	confiding	(3)	_____	+
	26	inoculation	(1)	_____	○
	27	consuming	(4)	_____	△
	28	gable	(4)	_____	☆
	29	apparition	(2)	_____	8
	30	emission	(3)	_____	+
	31	ambulation	(2)	_____	○
	32	saltation	(4)	_____	△

Calculating Raw Score

Ceiling item _____

minus errors _____

Raw score _____

Transfer raw score to test record overleaf, in top right hand corner

* To record errors, make oblique strokes through the geometric figures. Every sixth figure is identical to facilitate the determination of the basal or ceiling.

APPENDIX 6

ASTHMA MANAGEMENT ASSESSMENT

ASTHMA BEHAVIOURAL ASSESSMENT

1: Do you avoid things that you know make you wheeze or have an asthma attack

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

2: Do you avoid getting angry, worried or excited

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

3: Do you use your inhaler/puffer if you know you are going to get wheezy by what you are doing?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

4: Do you always remember to keep your inhaler with you or near you?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

5: If you feel wheezy do you tell yourself to calm down?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

6: When you are wheezy do you use your inhaler?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

7: When you are wheezy or have an attack do you try to breath more slowly?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

8: When you are wheezy or have an attack do you rest?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

9: When you are wheezy do you find a grown up to help you?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

10: When you are wheezy do you try to help yourself first?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

11: When you use your inhaler do you take as many puffs as you are supposed to?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

12: Do you use your inhaler as many times a day as you have been told to?

NEVER NOT MUCH SOMETIMES OFTEN ALWAYS

13: Do you talk or explain about your asthma to your friends?

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

14: Do you think that you look after your asthma on your own without help from parents

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

15: Do you do things to beat your asthma like finding other ways of enjoying yourself?

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

16: Do you sometimes use your asthma to get what you want or your own way ®

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

17: Do you hope that other people wont know that you have asthma ®

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

18: Do you forget to take your medicine on purpose?

NEVER ☐ NOT MUCH ☐ SOMETIMES ☐ OFTEN ☐ ALWAYS ☐

APPENDIX 7

CHILDHOOD ASTHMA QUESTIONNAIRE

FORM B

CHILDHOOD ASTHMA QUESTIONNAIRE

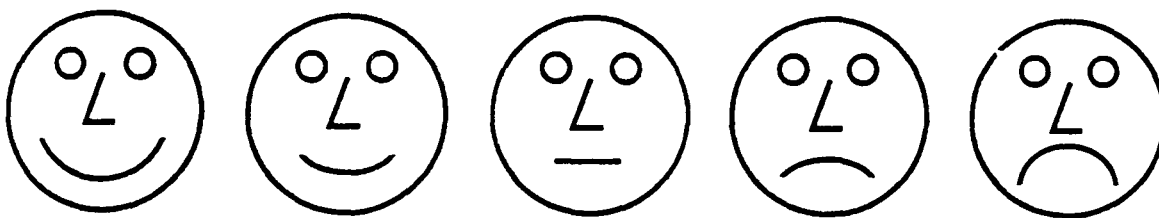
FORM B

INSTRUCTIONS

We would like to find out how you feel about the things you do at home and at school.

What we'd like you to do is colour in faces to show how you feel about these things or colour in boxes to show how often you do things.

Here are the faces you are going to be looking at:



The first one is a very happy face; the next face is quite a happy face and the one in the middle is neither happy or unhappy. The fourth face is quite an unhappy face, and the one on the far right is a very unhappy face. When you answer the questions we'd like you to colour in the face which describes how you feel.

Here are the boxes you are going to be looking at. Sometimes they ask how often you do something and sometimes they ask how often you feel unwell with your asthma.

A lot	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sometimes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
Hardly ever	<input type="checkbox"/>	<input type="checkbox"/>		
Not at all	<input type="checkbox"/>			

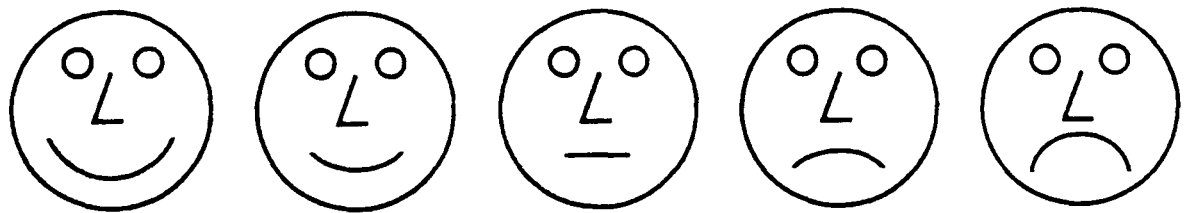
If you have been doing something a lot, or something (like getting wheezy) has happened to you a lot recently, then fill in the top line, four boxes. If it has happened sometimes, or you have done something sometimes, then fill in the three boxes on the second line. If you have hardly ever done that thing recently or have hardly ever had that problem with your asthma then colour in the two boxes marked 'hardly ever', and if it has not happened to you at all or you have not done that thing, then fill in the last line with only one box.

If you get stuck on a word, then please ask someone for help, but answer the questions yourself – we are interested in how you feel.

HOW YOU FEEL

For
Office
Use O

I. Which picture describes how you feel most of the time?

☐

2a. How often do you play outside when it is warm and sunny?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

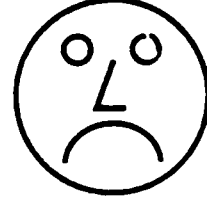
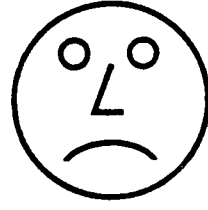
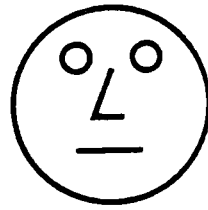
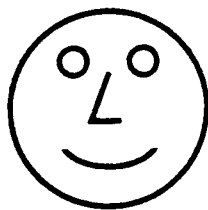
--	--

Not at all

--

☐

2b. Which picture describes how you feel when you play outside when it is warm and sunny?

☐

3a. How often do you play outside when it is cold?

A lot

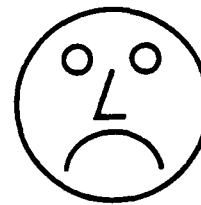
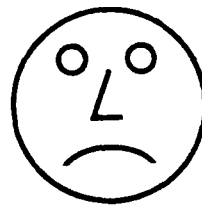
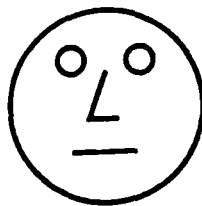
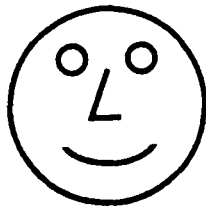
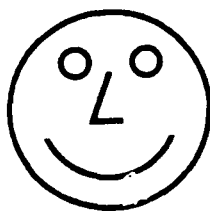
Sometimes

Hardly ever

Not at all

☐

3b. Which picture describes how you feel when you play outside when it is cold?

☐

4a. How often do you play inside with your toys?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

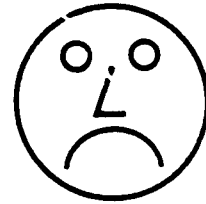
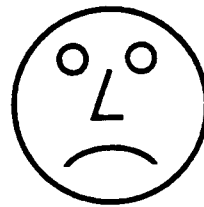
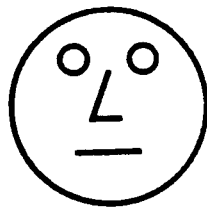
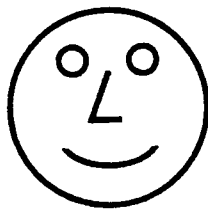
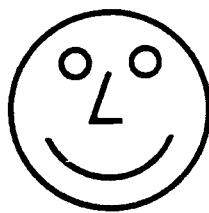
--	--

Not at all

--

☐

4b. Which picture describes how you feel when you play inside with your toys?

☐

5a. How often do you read books?

A lot

☐

Sometimes

☐

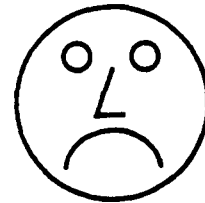
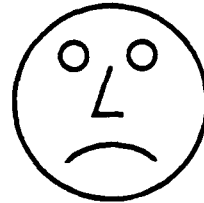
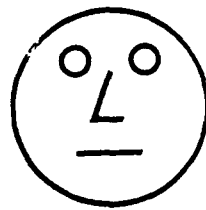
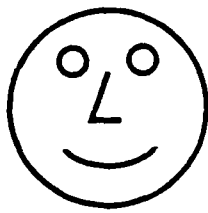
Hardly ever

☐

Not at all

☐☐

5b. Which picture describes how you feel when you read books?

☐

6a. How often do you draw pictures?

A lot

☐☐☐☐

Sometimes

☐☐☐

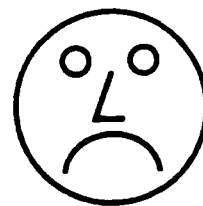
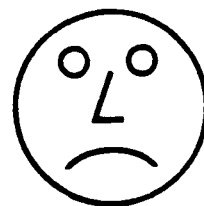
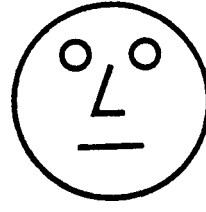
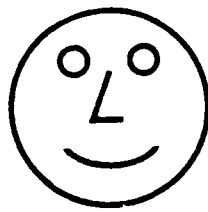
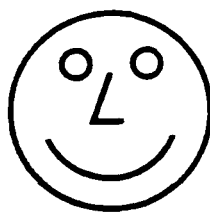
Hardly ever

☐☐

Not at all

☐☐

6b. Which picture describes how you feel when you draw pictures?

☐

7a. How often do you watch television?

A lot

--	--	--

Sometimes

--	--	--

Hardly ever

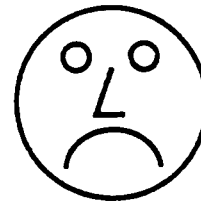
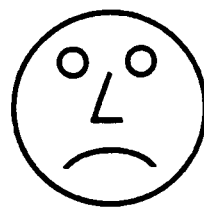
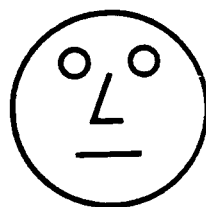
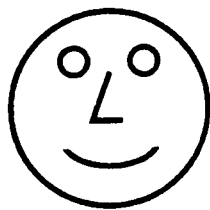
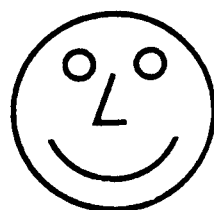
--	--

Not at all

--

☐

7b. Which picture describes how you feel when you watch television?

☐

8a. How often do you go to the swimming pool?

A lot

--	--	--	--

Sometimes

--	--

Hardly ever

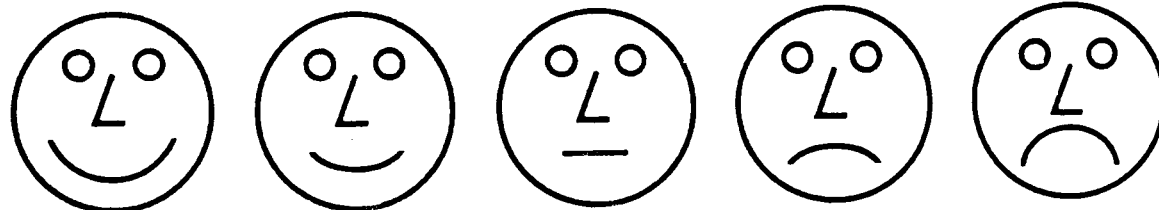
--	--

Not at all

--

☐

8b. Which picture describes how you feel about going to the swimming pool?

☐

9a. How often do you do P.E. at school?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

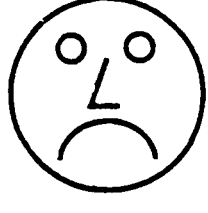
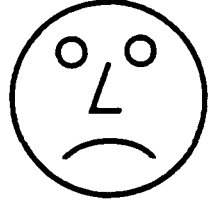
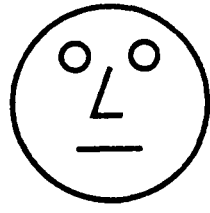
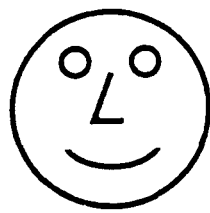
--	--

Not at all

--

☐

9b. Which picture describes how you feel when you do P.E. at school?

☐

10a. How often do you play games outside (like ball games) with your class?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

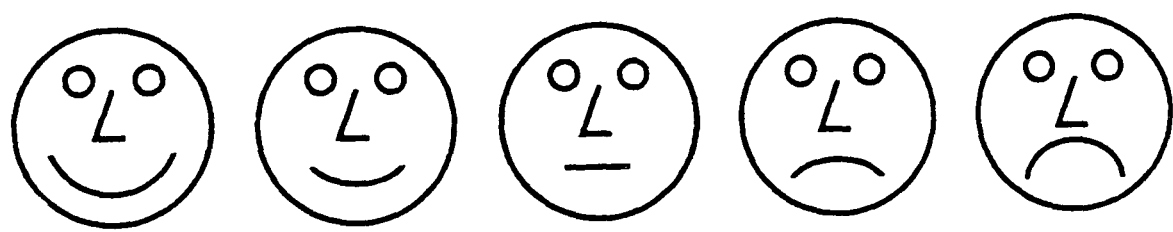
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Not at all

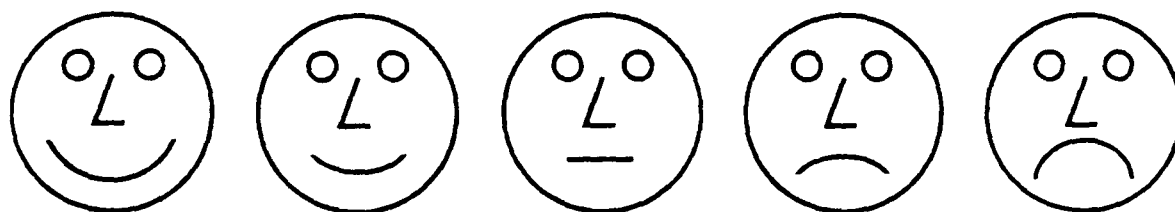
--

☐

10b. Which picture describes how you feel when you play games outside (like ball games) with your class?

☐

11. Which picture describes how you feel about running around at playtimes?

☐

12. How often have you had headaches recently?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

--	--

Not at all

--

☐

13. How often have you had tummy aches recently?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

--	--

Not at all

--

☐

14. How often have you had coughs or colds recently?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

--	--

Not at all

--

--

15. How often have you missed school because you were not feeling well?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

--	--

Not at all

--

--

ABOUT YOUR ASTHMA

For
Office
Use Or

16a. How much have you been wheezing (or getting tight in the chest) recently?

A lot

☐☐☐☐

Sometimes

☐☐☐

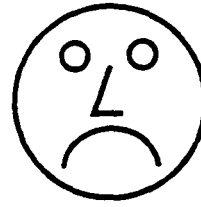
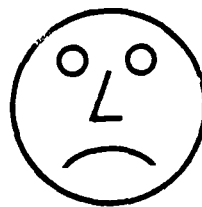
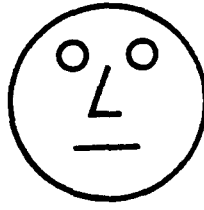
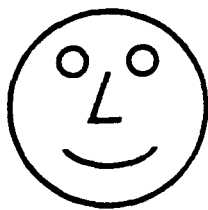
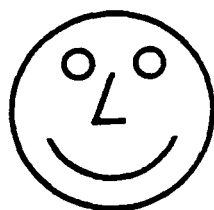
Hardly ever

☐☐

Not at all

☐☐

16b. Which picture describes how you feel when you are wheezy or tight-chested?

☐

17a. How much have you been coughing recently?

A lot

☐☐☐☐☐

Sometimes

☐☐☐

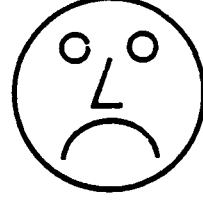
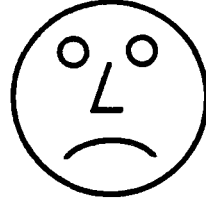
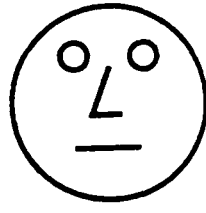
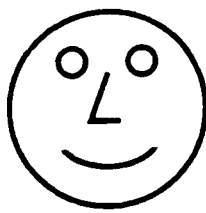
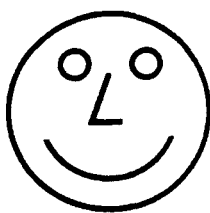
Hardly ever

☐☐

Not at all

☐☐

17b. Which picture describes how you feel when you cough?

☐

18a. How much have you been waking up at night with your asthma recently?

A lot

☐☐☐☐

Sometimes

☐☐☐

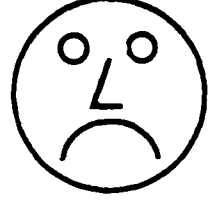
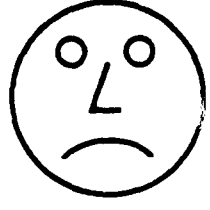
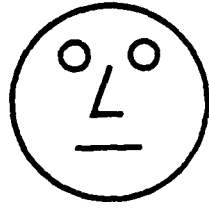
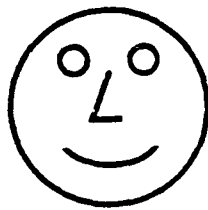
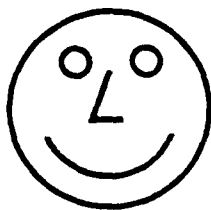
Hardly ever

☐☐

Not at all

☐☐

18b. Which picture describes how you feel when you wake at night with your asthma?

☐

19a. How often have you had asthma attacks recently?

A lot

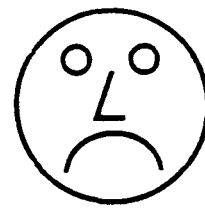
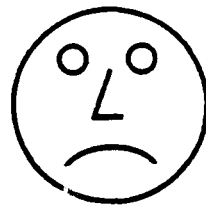
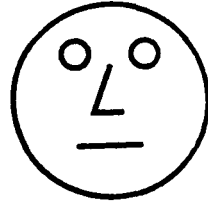
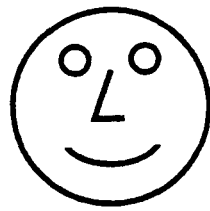
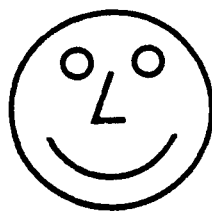
Sometimes

Hardly ever

Not at all

☐

19b. Which picture describes how you feel when you are having an asthma attack?

☐

20a. How often have you missed school because of your asthma recently?

A lot

--	--	--	--

Sometimes

--	--	--

Hardly ever

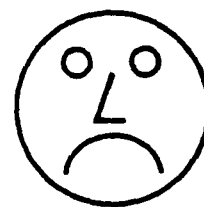
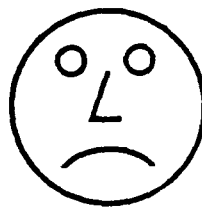
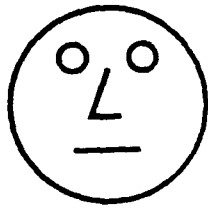
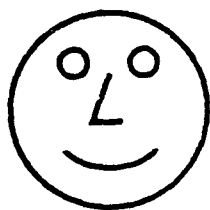
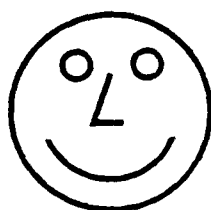
--	--

Not at all

--

☐

20b. Which picture describes how you feel when you miss school because of your asthma?

☐

21a. Do you use your inhaler (your medicine) when you're supposed to?

A lot/always

☐

Sometimes

☐

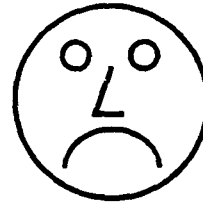
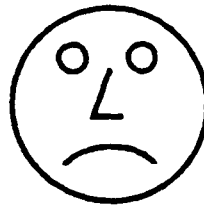
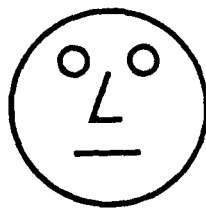
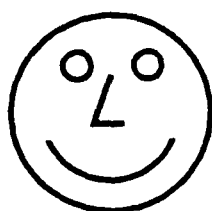
Hardly ever

☐

Not at all

☐☐

21b. Which picture describes how you feel without your inhaler if you're feeling wheezy?

☐

22a. How bad do you think your asthma has been recently?

Not too bad

☐

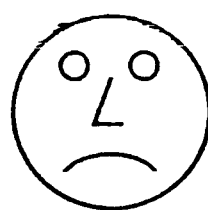
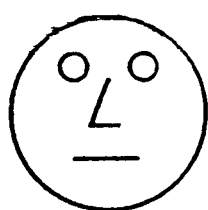
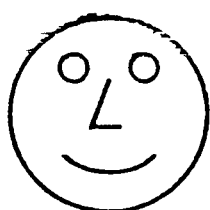
Quite bad

☐

Very bad

☐

22b. How do you feel about having asthma?



APPENDIX 8
CHILDHOOD ASTHMA QUESTIONNAIRE
FORM C

CHILDHOOD ASTHMA QUESTIONNAIRE

FORM C

INSTRUCTIONS


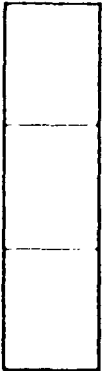


We are interested in how young people who have asthma feel about themselves and the things that they do, how they feel about having asthma and if they think it affects their lives. Your answers will be kept completely confidential so please do your best to answer all of the questions truthfully.

Over the page is an example of how to answer the questions. When a question asks 'How often?' you should place a number between one and four in the box – 4 if you do that thing or experience it often or very often; 3 if you do or experience it sometimes, 2 if you hardly ever do or experience the thing in the question, and 1 if you do not do it at all or it never happens.

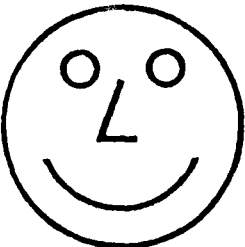
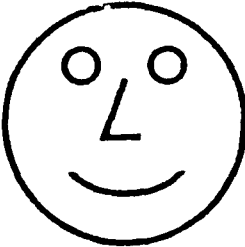
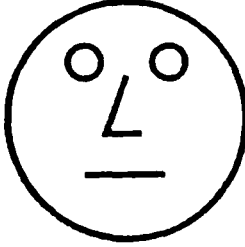
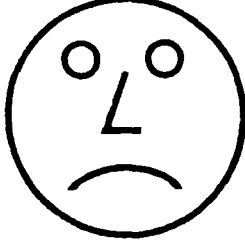
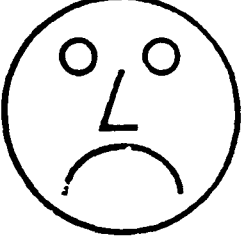
When a question asks 'How do you feel?' you should place a number between one and five in the box, as if you were giving it marks out of five for how much you like it – 5 if you like it a lot, 4 if you quite like it, 3 if you don't mind or don't care one way or the other, 2 if you don't really enjoy it, and 1 if you hate it. Do not use zero. There will be a reminder on every page of what the numbers mean in case you need it.

Now turn the page and try the example.

How often?

4	3	2	1
			
A lot or very often, or all of the time.	Sometimes, or some of the time.	Hardly ever or not very often.	Never or not at all.

How do you feel?

5	4	3	2	1
				
Great! or I really like it or I am very happy when I am doing this.	OK or I quite like it or I am fairly happy doing this.	I don't mind, I don't like or dislike it.	I don't really like this or it makes me a bit unhappy.	I hate this or it makes me very unhappy to do this.

How often do you watch television?

How do you feel about watching television?

If you think that you watch television a lot and it is something that you really like to do then you would answer 4 to the first question and 5 to the second.

If you only watch sometimes and don't really mind whether you do or not, you don't like or dislike it, then you would answer 3 to the first question and 3 to the second.

If you really hate watching TV then you would answer 1 to the second question.

Are you happy that you know how to answer the questions? If not ask someone to help you with the example. If you feel that you understand then turn the page and answer the questions. On every page there will be a reminder of what the numbers mean in case you need it.

How often:

4



A lot or very often, or all of the time.

3



Sometimes, or some of the time.

2



Hardly ever or not very often.

1



Never or not at all.

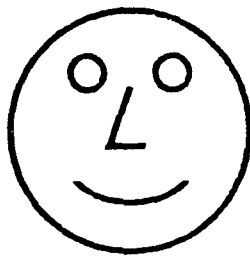
How do you feel?

5



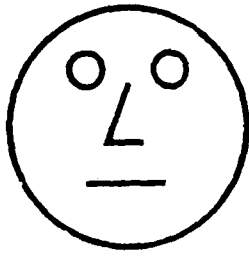
Great! or I really like it or I am very happy when I am doing this.

4



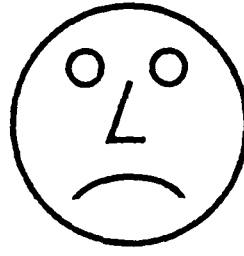
OK or I quite like it or I am fairly happy doing this.

3



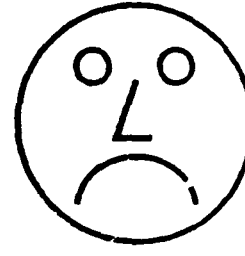
I don't mind, I don't like or dislike it.

2



I don't really like this or it makes me a bit unhappy.




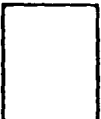
1



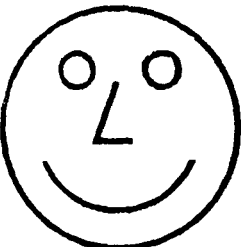
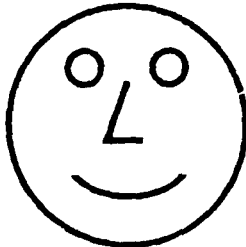
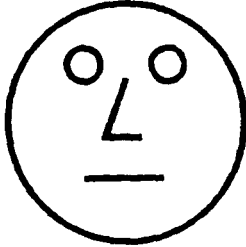
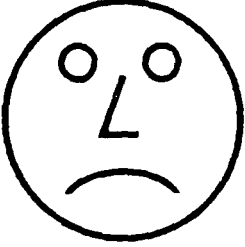

I hate this or it makes me very unhappy to do this.

- 1a. How often do you read books or magazines?
- b. How do you feel about reading books or magazines?
- 2a. How often do you go to the swimming pool?
- b. How do you feel about going to the swimming pool?
- 3a. How often do you go to discos or parties?
- b. How do you feel about going to discos or parties?
- 4a. How often do you dance at discos or parties?
- b. How do you feel about dancing at discos or parties?
- 5a. How often do you do P.E. or gym indoors?
- b. How do you feel about doing P.E. or gym indoors?
- 6a. How often do you do sports or games outside?
- b. How do you feel about doing sports or games outside?
- 7a. How often do you go out when the weather is fine?
- b. How do you feel about going out when it is fine?
- 8a. How often do you go out when the weather is cold?
- b. How do you feel about going out when it is cold?

How often?

4	3	2	1
			
A lot or very often, or all of the time.	Sometimes, or some of the time.	Hardly ever or not very often.	Never or not at all.

How do you feel?

5	4	3	2	1
				
Great! or I really like it or I am very happy when I am doing this.	OK or I quite like it or I am fairly happy doing this.	I don't mind, I don't like or dislike it.	I don't really like this or it makes me a bit unhappy.	I hate this or it makes me very unhappy to do this.

On this page, if your answer is **1**, (**never**) to part **a** of any question, you should miss out part **b** of that question. The questions on this page are about your asthma in the past few weeks.

9a. How often have you been wheezy or tight-chested recently?

b. How do you feel about getting wheezy or tight-chested?

10a. How much have you coughed recently?

b. How do you feel about coughing?

11a. How often have you had asthma attacks recently?

b. How do you feel about having asthma attacks?

12a. How often have you woken at night with asthma recently?

b. How do you feel about waking at night with asthma?

13a. How often have you missed school because of asthma recently?

b. How do you feel about missing school because of asthma?

14a. How often do animals make you cough or wheeze?

b. How do you feel about having to avoid animals?

15a. How often does running make you cough or wheeze?

b. How do you feel about getting asthma when you run?

How often?

4



A lot or very often, or all of the time.

3



Sometimes, or some of the time.

2



Hardly ever or not very often.

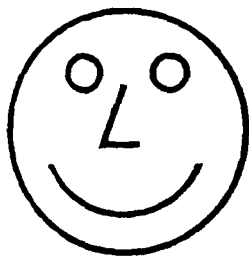
1



Never or not at all.

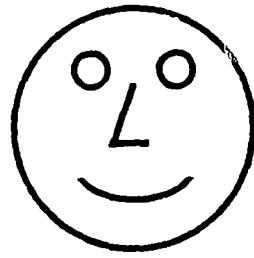
How do you feel?

5



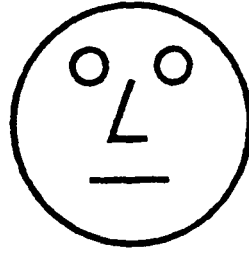
Great! or I really like it or I am very happy when I am doing this.

4



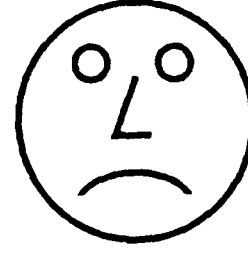
OK or I quite like it or I am fairly happy doing this.

3



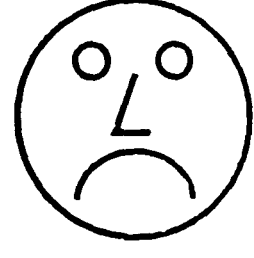
I don't mind, I don't like or dislike it.

2



I don't really like this or it makes me a bit unhappy.

1



I hate this or it makes me very unhappy to do this.

16. How do you feel about making new friends?
17. How do you feel about having to carry your inhaler?
18. How do you feel about having to avoid things that make you cough or wheeze?
19. How do you feel when parents or teachers fuss over you?
20. How do you feel about telling other people that you have asthma?
21. How do you feel about people around you smoking?
22. How do you feel about having a cigarette yourself?
23. How do you feel about finding that you have forgotten your inhaler?
24. How do you feel about having asthma?
25. How often have you had headaches recently?
26. How often have you had stomach aches recently?
27. How often have you missed school because you were not well recently?
28. How often do you get coughs and colds?

29. How bad do you think your asthma is? (tick one box)

Not too ☐

Quite bad ☐

Very bad ☐

☐

30. How well do you think that your medicine is working at the moment? (tick one box)

Very well ☐

Quite well ☐

Not at all ☐

☐

31. Does anyone else in your close family have asthma?
Please tell us what relation they are to you?

☐

APPENDIX 9
PARENTAL BACKGROUND SHEET

PARENTS INFORMATION

Please answer all questions.

1: How old is your child ?

2: How many years has he/she had asthma ?

3: Do you have other children? If yes how many.

4: What medication has your child been prescribed please put name of drug/inhaler, the dose and the number of times a day they should take them. If a when needed dose please state.

Name of drug/inhaler	Dose	How often

5: How many times have you needed to take your child to your family doctor for his/her asthma in the last TWO months.

None

☐

One

☐

Two to Three

☐

Four or more

☐

6: How many times have you needed to take your child to the casualty department for his/her asthma in the last TWO months.

None

☐

One

☐

Two to Three

☐

Four or more

☐

7: How well controlled is your child's asthma at the moment?

Very well controlled

☐

Quite well controlled

☐

Not at all well controlled

☐

8: How many school days has your child lost in the past TWO months because of his/her asthma?

None at all

☐

1 or 2 days

☐

3 to 5 days

☐

5 to 10 days

☐

More than 10 days

☐

9: How often have you been woken at night by your child's asthma in the past TWO months?

Not at all

☐

Once a week or less

☐

Several nights a week

☐

Almost every night

☐

10: How would you rate the severity of your child's asthma at the moment?

Mild

☐

Moderate

☐

Severe

☐

11: How much would you say that your child's asthma is affecting the rest of your family at the moment?

Not at all

☐

A little

☐

Quite a lot

☐

A great deal

☐

12: Does anyone else in your close family have asthma? please tell us how they are related to your child.

13: Is your house/flat

Owned

☐

Rented

☐

14: How many cars do you have in your household?

None

☐

One

☐

Two or more

☐

APPENDIX 10
PARENTAL CONSENT FORM

CONSENT FORM FOR PARENTS

I _____

of SALOMONS CENTRE, TUNBRIDGE WELLS, KENT have fully explained to this parent

the nature and purpose of the research project on children's understanding and beliefs about childhood asthma and they have consented to participate and give consent for their child _____ to participate.

I have given them a copy of the information sheet about this research project and have answered their questions. They have kept the information sheet for future reference.

Signature of investigator _____ Date _____

Name _____

PARENT CONSENT ON THEIR OWN BEHALF AND ON BEHALF OF THEIR CHILD.

I _____

hereby consent for myself and my child to take part in the above investigation, the nature and purpose of which have been explained to us. Any questions I or my child wish to ask have been answered to our satisfaction. I understand that we may withdraw from the investigation at any stage and this will in no way affect the care I or my child receive as a patient.

Signed.

Participant _____ Date _____

APPENDIX 11

INFORMATION SHEET FOR PARENTS

INFORMATION TO PARENTS

Dear parent s

Childhood asthma is now a common condition and children's knowledge and understanding of their illness changes as they grow. At some point managing their asthma and treatment will increasingly become something the child has to deal with. So far there has been little research that has asked children directly about their experience of asthma and their understanding about their condition and how to manage it. This research aims to gain a greater understanding of what is important for successful adjustment to having asthma and how to help children with this.

I aim to talk to children with asthma aged between 8-16 years, the interview will take less than an hour and is structured not to be difficult. A parent will also be asked to fill in some short questions about their child's asthma. All information will be treated confidentially and names and other identifying information will not be used in the research. Your decision to take part or not is voluntary and will not in any way affect the treatment you receive or may receive from the professionals who look after you and your child.

If you have any further questions about this research please contact

Psychology Department
Salomons Centre
Broomhill Road
Southborough
Tunbridge Wells
Kent
Tel: 01892- 515152

Thank you very much for your co-operation.

Yours sincerely

Psychologist in Clinical Training

APPENDIX 12

RESULTS OF LEVENE TESTS FOR HOMOGENEITY OF VARIANCE

RESULTS OF LEVENE TESTS FOR HOMOGENEITY OF VARIANCE

VARIABLE	LEVENE STATISTIC	SIGNIFICANCE	DEGREES OF FREEDOM
Gender	17.186	.000 ***	39
Severity	2.139	.152	39
Deprivation	4.403	.042 *	39
Knowledge	.001	.917	39
Asthma Control	.024	.878	39
Adherence	1.100	.301	39
Illness Identity	.365	.549	39
Consequences	.324	.573	39
Timeline	.152	.699	39
Control/Cure	.151	.699	39
Pollution	2.095	.156	38
Others	.099	.755	39
Medical Care	29.929	.000 ***	38
Hereditary	.123	.728	39
Stress/Worry	2.147	.151	39
Emotional	3.290	.077	39
Food Allergy	4.657	.037 *	39
Bad Luck	.433	.514	39
Poor self-care	.408	.527	39
Germ/Virus	7.921	.008 **	38

Significant at * $p \leq .05$; ** $p \leq .02$; *** $p \leq .001$

APPENDIX 13

RESULTS OF CORRELATIONS ON DEMOGRAPHIC INDICES

GROUP 1 & 2

Correlations between Demographic Variables and Illness Representations, Knowledge, Adherence, Control and Quality of Life Measures for Group 1.

VARIABLE	Gender Tau-C	Severity R	Duration R	Deprivation R
Illness Identity	.370 p=.950	r=-.1138 p=.653	-.2825 p=.256	-.1907 p=.449
Consequences	.086 p=.058	.1202 p=.635	-.0192 p=.719	.0794 p=.754
Control/Cure	-.037 p=.782	.1565 p=.535	.4258 p=.078	.1184 p=.640
Timeline	.172 p=.234	.1049 p=.679	.4739 p=.047*	.0516 p=.839
Pollution	-.098 p=.541	.2707 p=.277	.1414 p=.576	.3338 p=.176
Others	-.222 p=.057	-.0331 p=.896	.2753 p=.269	-.0766 p=.762
Medical Care	-.185 p=.073	-.0059 p=.981	-.0074 p=.977	.1536 p=.543
Hereditary	.148 p=.516	.2649 p=.288	.1162 p=.646	.2744 p=.270
Stress/Worry	.000 p=1.00	-.1315 p=.603	.0339 p=.894	.2003 p=.425
Emotional	.098 p=.587	.1240 p=.624	.2526 p=.312	-.0574 p=.821
Food Reaction	-.098 p=.631	.0630 p=.804	.2542 p=.309	.0728 p=.774
Bad Luck	-.086 p=.602	-.1922 p=.445	.3161 p=.201	.3554 p=.148
Poor Self Care	.407 p=.098	.4219 p=.081	.1542 p=.541	-.1301 p=.607
Germ/Virus	-.544 p=.026 *	-.3101 p=.211	-.0379 p=.881	-.0699 p=.738
Active Quality of Life	-.283 p=.107	-.1778 p=.480	-.1074 p=.672	.5214 p=.026*
Passive Quality of Life	-.061 p=.812	.0042 p=.987	-.1595 p=.527	.5526 p=.017*
Subjective Severity	.111 p=.450	.2530 p=.311	.0948 p=.708	.0096 p=.970
Subjective Distress	.483 p=.045 *	.0816 p=.748	.0511 p=.840	-.3866 p=.113
Days Off School	.0894 p=.724	.2233 p=.373	.4198 p=.083	.2294 p=.360
Nights Disturbed	.2548 p=.307	-.0141 p=.956	.5758 p=.012*	.1830 p=.467
GP Visists	.055 p=.827	-.1692 p=.502	-.1567 p=.535	-.1565 p=.535
Adherence	-.209 p=.478	-.0079 p=.975	.0548 p=.829	.2904 p=.242
Knowledge	-.111 p=.590	.0851 p=.737	.2133 p=.395	.0393 p=.877

* p < .05; ** p < .02; *** p < .001.

Associations between Demographic variables and Illness Representations, Knowledge, Adherence, Control and Quality of life for group 2

VARIABLE	Gender Tau- C	Severity	Duration	Deprivation
Illness Identity	.015 p=.950	r=-.4104 p=.052	r=-.0434 p=.844	r=-.1481 p=.50
Consequences	.204 p=.380	r=-.0092 p=.653	r=-.3038 p=.159	r=-.1054 p=.631
Control/Cure	-.476 p=.018 *	r=-.2610 p=.833	r=-.0745 p=.735	r=-.0257 p=.907
Timeline	.370 p=.091	r=-.3802 p=.074	r=-.2703 p=.212	r=-.3456 p=.106
Pollution	-.325 p=.109	r=-.2934 p=.174	r=-.1521 p=.488	r=-.1129 p=.608
Others	.143 p=.488	r=-.0324 p=.883	r=-.1368 p=.534	r=-.3503 p=.101
Medical Care	-----	-----	-----	-----
Hereditary	.302 p=.184	r=-.2864 p=.195	r=-.1812 p=.408	r=-.3337 p=.120
Stress/Worry	.098 p=.660	r=-.3874 p=.068	r=-.4848 p=.019*	r=-.1202 p=.585
Emotional	-.045 p=.816	r=-.0573 p=.795	r=-.3533 p=.098	r=-.0030 p=.989
Food Reaction	.098 p=.678	r=-.1180 p=.592	r=-.0189 p=.932	r=-.1853 p=.397
Bad Luck	-.241 p=.257	r=-.0059 p=.979	r=-.0504 p=.819	r=-.0737 p=.738
Poor Self Care	-.332 p=.098	r=-.2839 p=.189	r=-.3015 p=.162	r=-.0311 p=.888
Germ/Virus	-.544 p=.003 *	r=-.2186 p=.316	r=-.1454 p=.507	r=-.1829 p=.404
Active Quality Of Life	r=-.7056 p=.000*	r=-.0194 p=.930	r=-.2794 p=.197	r=-.1762 p=.421
Teenage Quality of life	-.037 p=.881	r=-.0465 p=.833	r=-.3741 p=.079	r=-.2096 p=.3337
Subjective Severity	-.325 p=.166	r=-.0963 p=.662	r=-.0951 p=.666	r=-.0365 p=.869
Subjective Distress	.3874 p=.068	r=-.1862 p=.395	r=-.1742 p=.427	r=-.0862 p=.696
Reactivity	.045 p=.854	r=-.3844 p=.070	r=-.0682 p=.757	r=-.0887 p=.687
Days Off School	.168 p=.442	r=-.3567 p=.095	r=-.3168 p=.141	r=-.3550 p=.097
Nights Disturbed	.186 p=.395	r=-.1309 p=.552	r=-.2996 p=.165	r=-.3379 p=.115
GP Visits	.137 p=.531	r=-.0687 p=.755	r=-.0989 p=.654	r=-.0857 p=.698
Knowledge	.431 p=.040 *	r=-.5633 p=.014*	r=-.1856 p=.397	r=-.0487 p=.825
Adherence	-.257 p=.264	r=-.1976 p=.366	r=-.1961 p=.370	r=-.1361 p=.536

* p < .05; ** p < .02; *** p < .001.

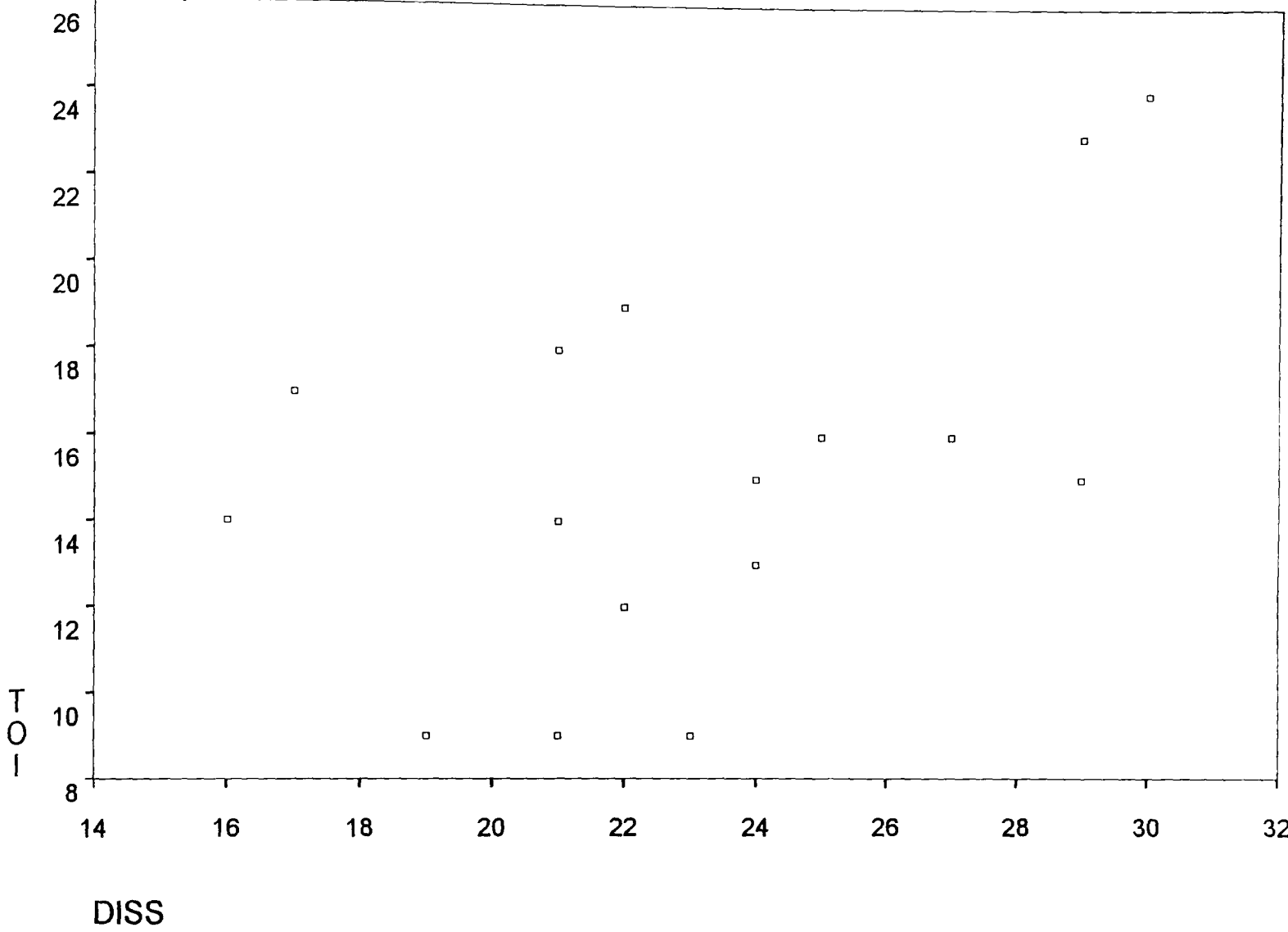
APPENDIX 14

SCATTERGRAMS OF SIGNIFICANT CORRELATIONS

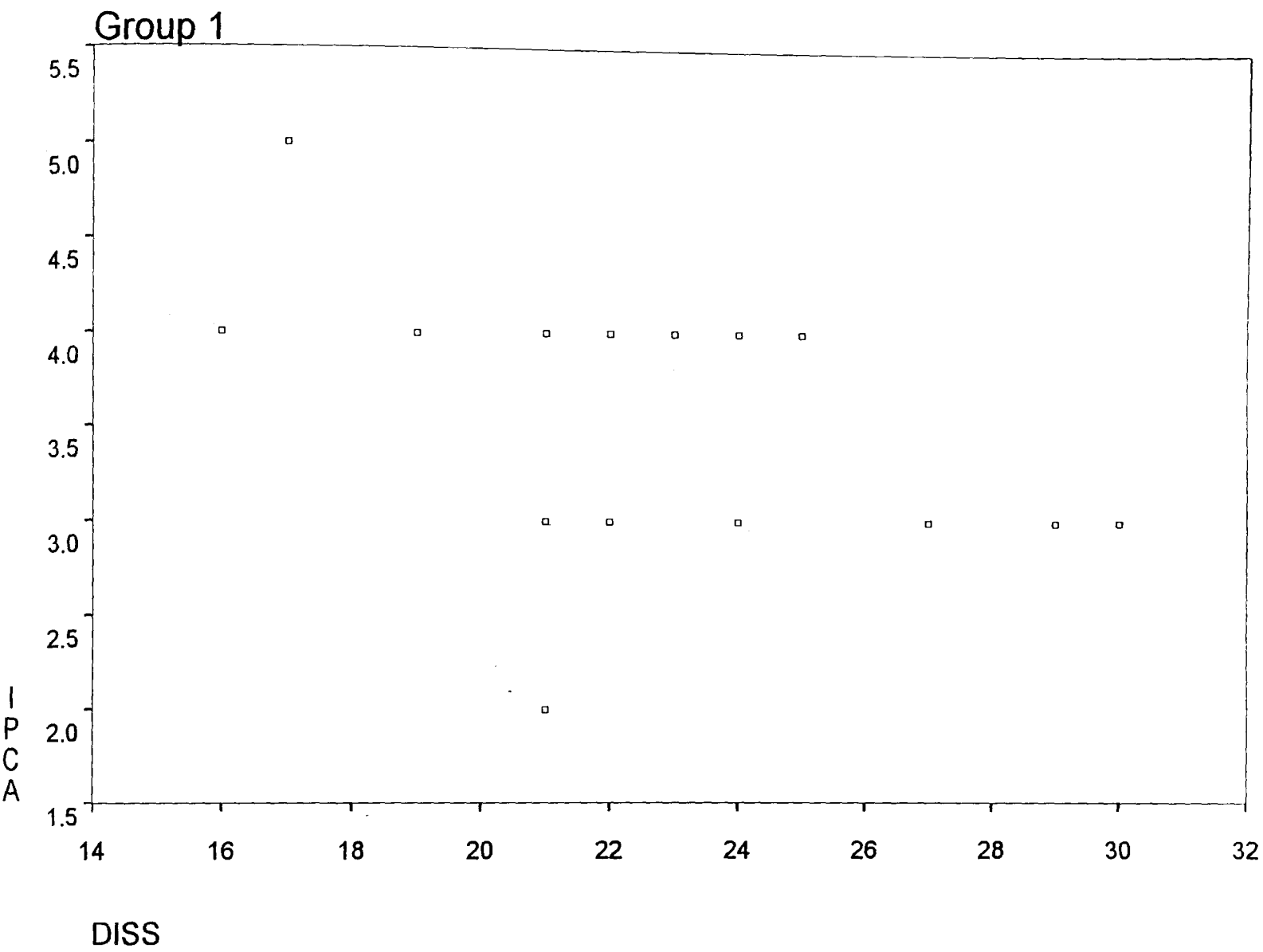
GROUP 1 & 2

Subjective Distress with Illness Identity

Group 1

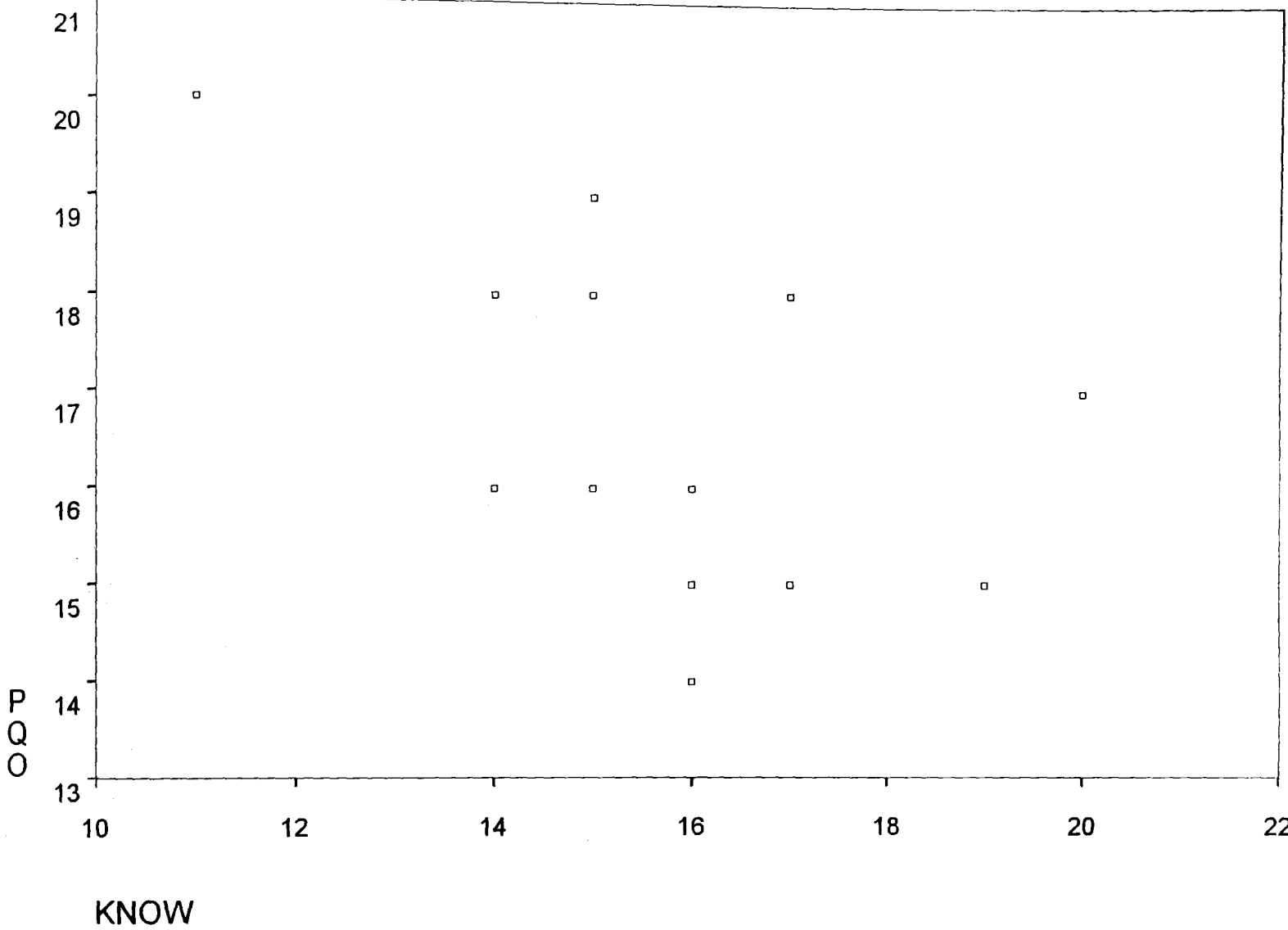


Subjective Distress with Pollution



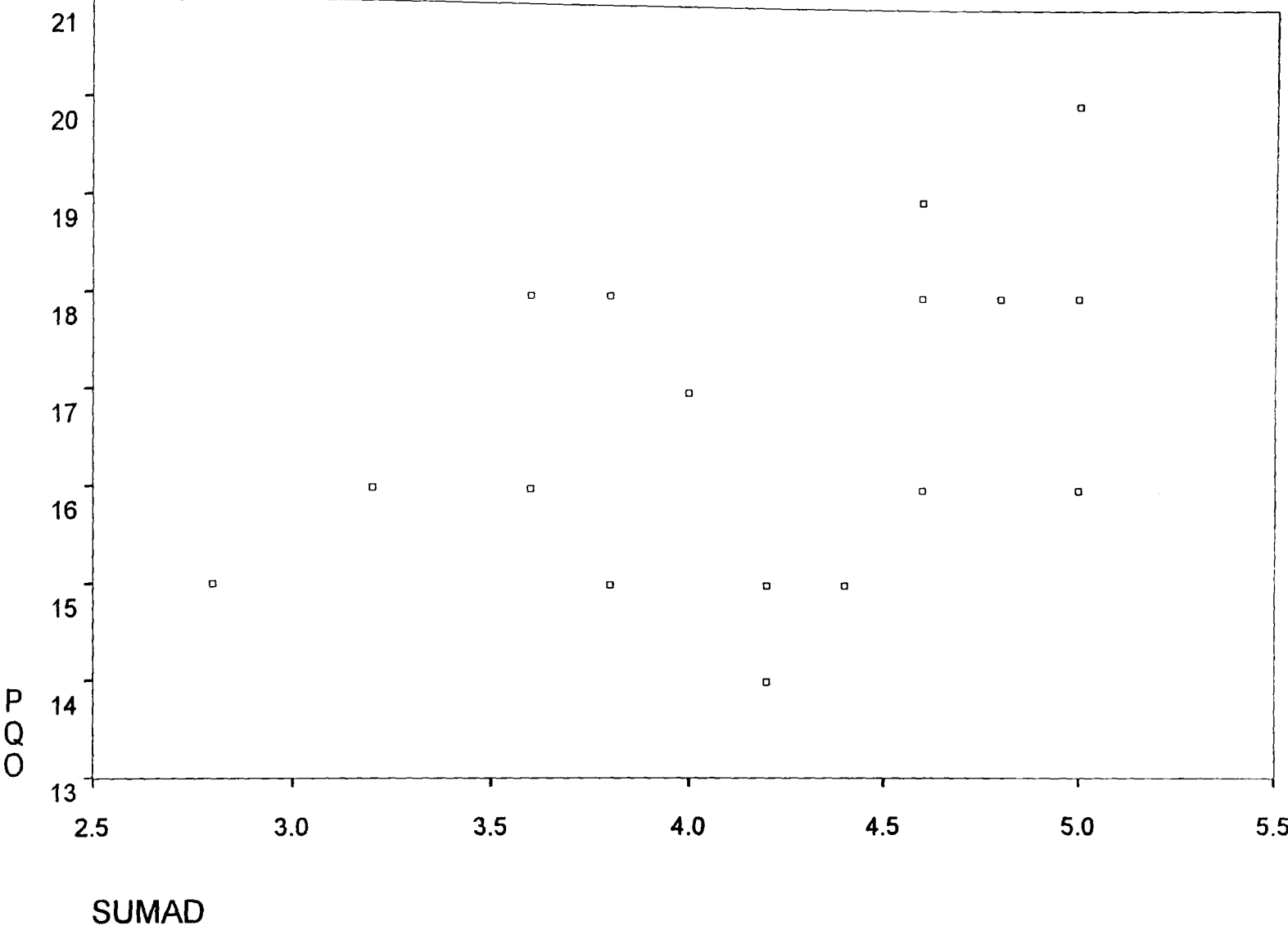
Knowledge with Passive Quality of Life

Group 1



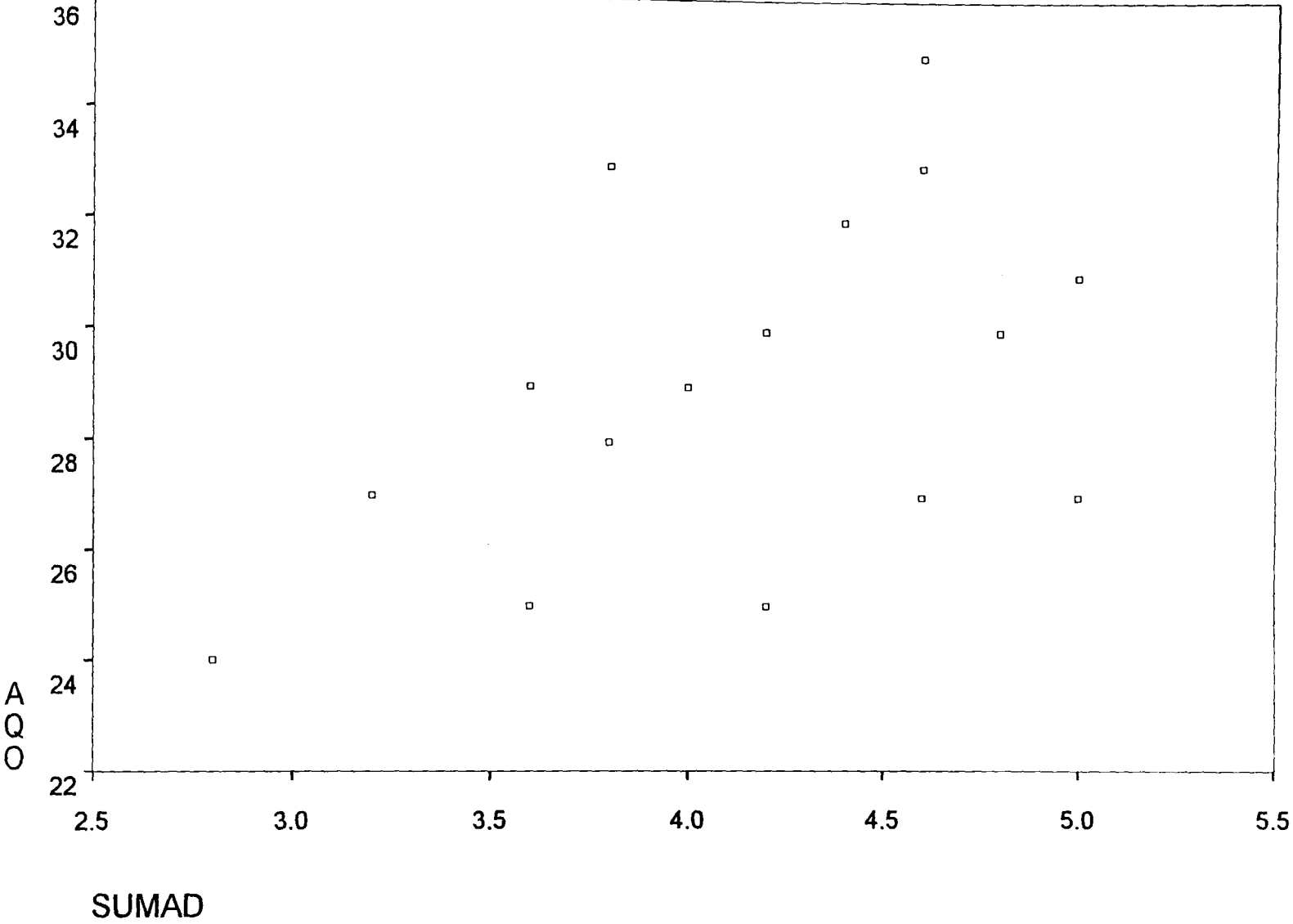
Adherence with Passive Quality of Life

Group 1



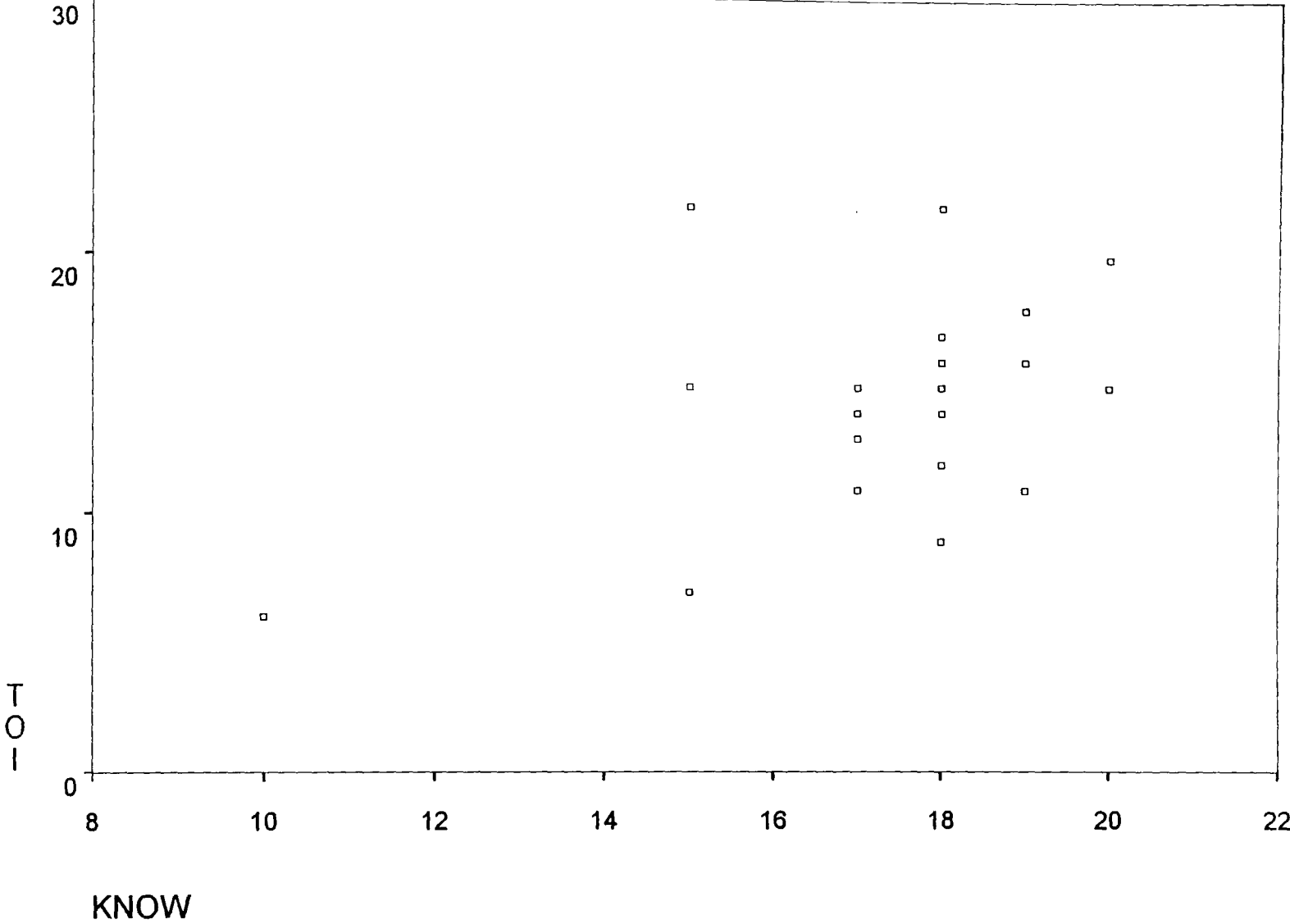
Adherence with Active Quality of Life

Group 1

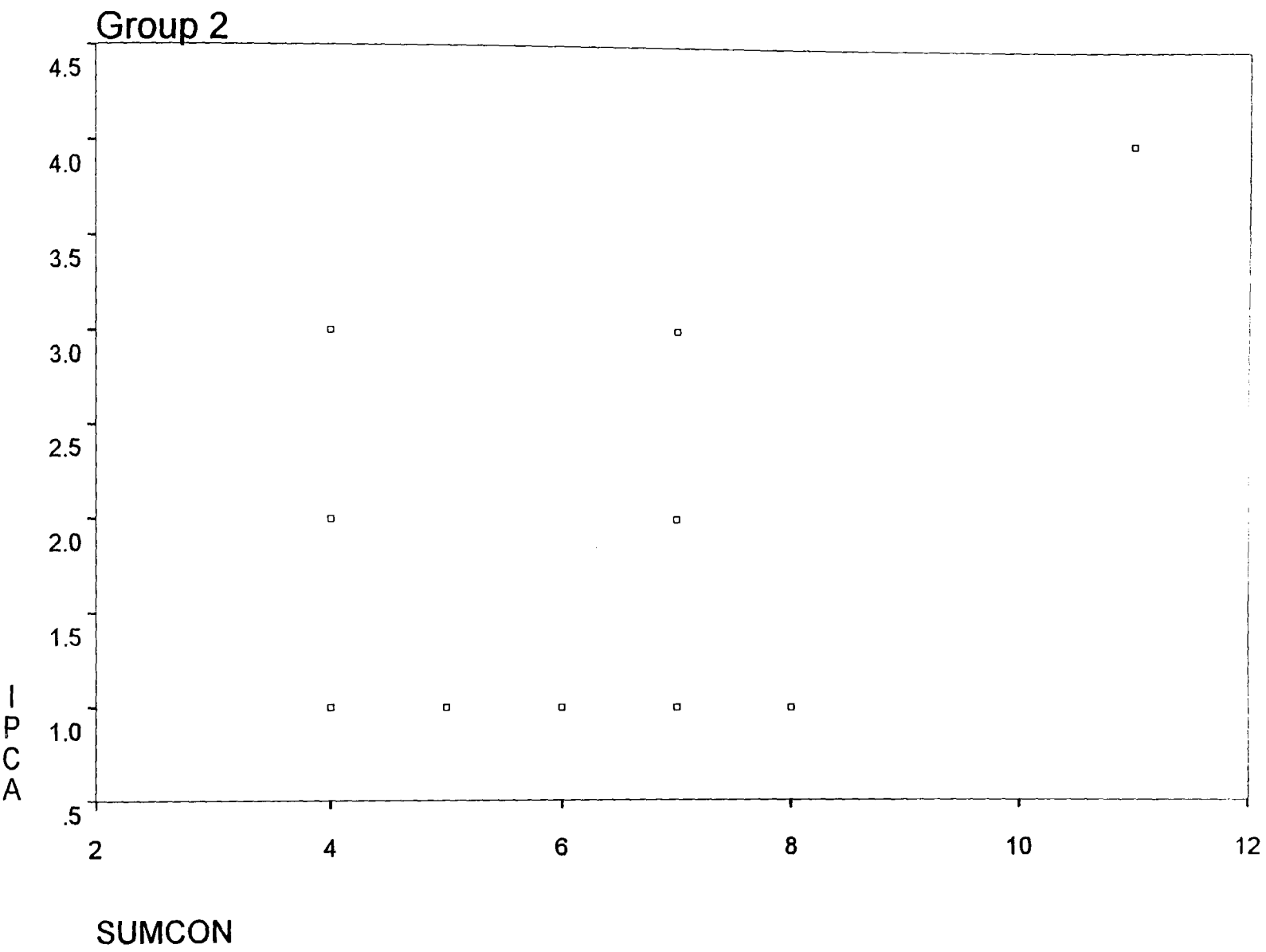


Knowledge with Illness Identity

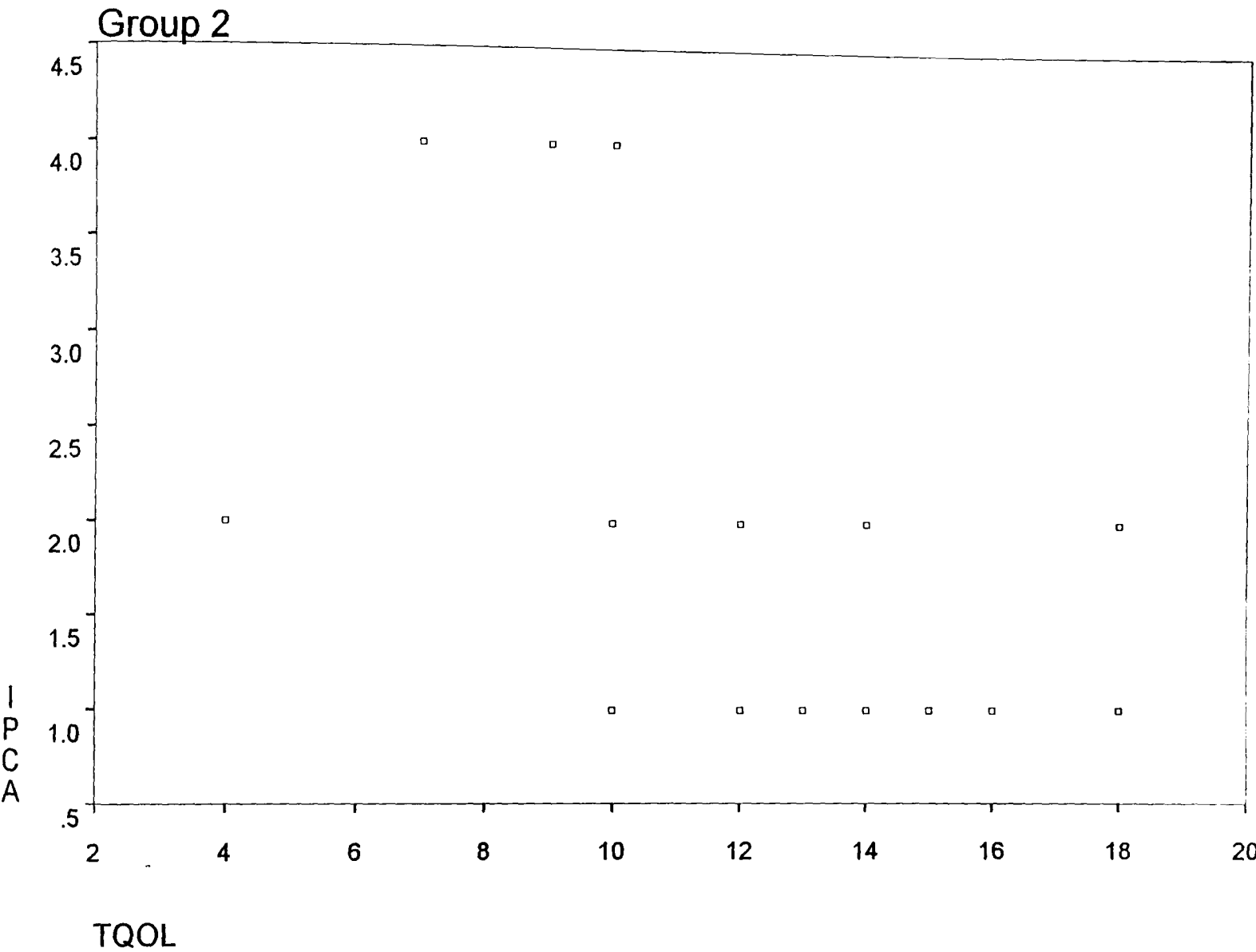
Group 2



Asthma Control with Emotional Causes

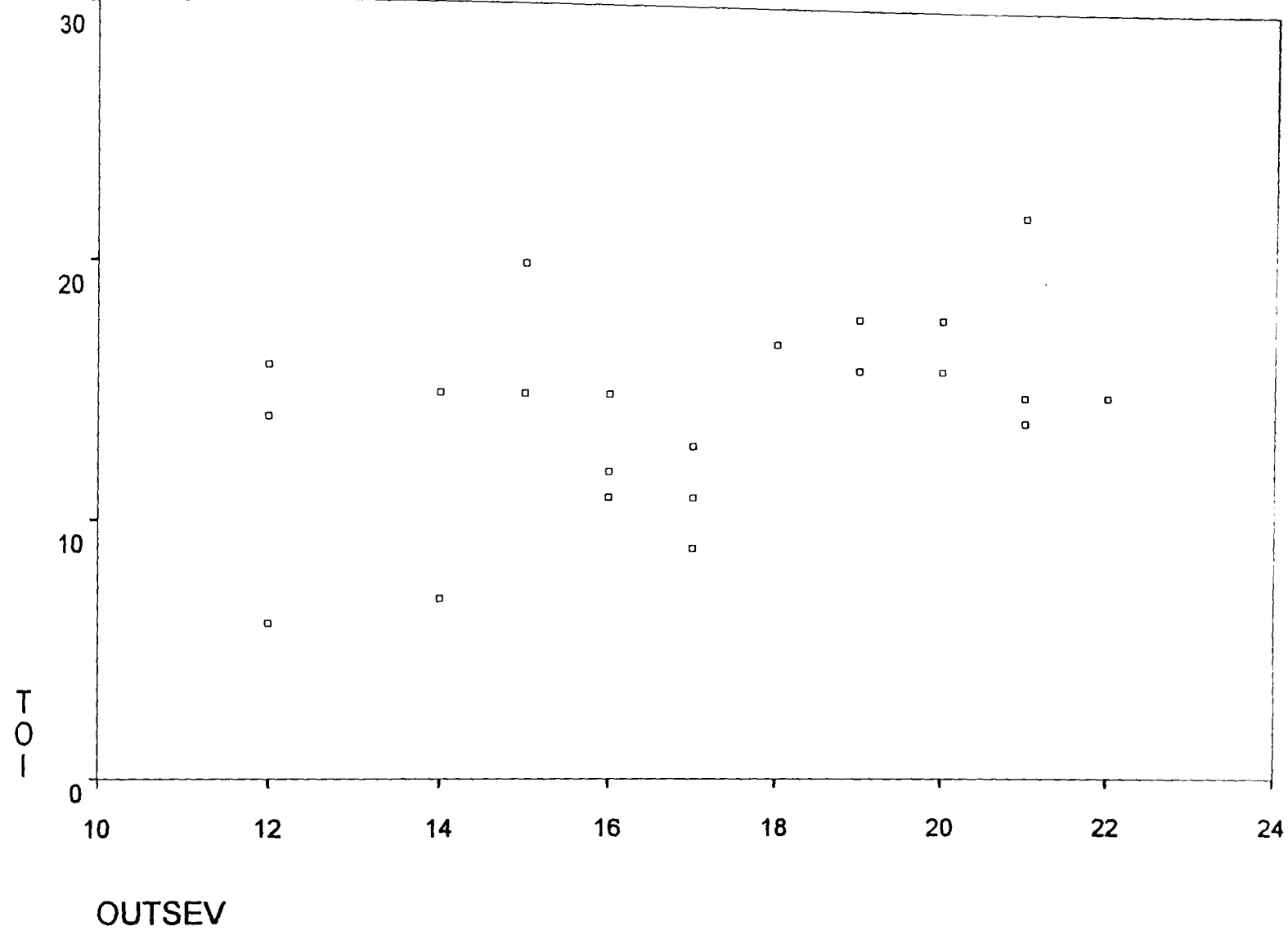


Teenage Quality of Life with Others



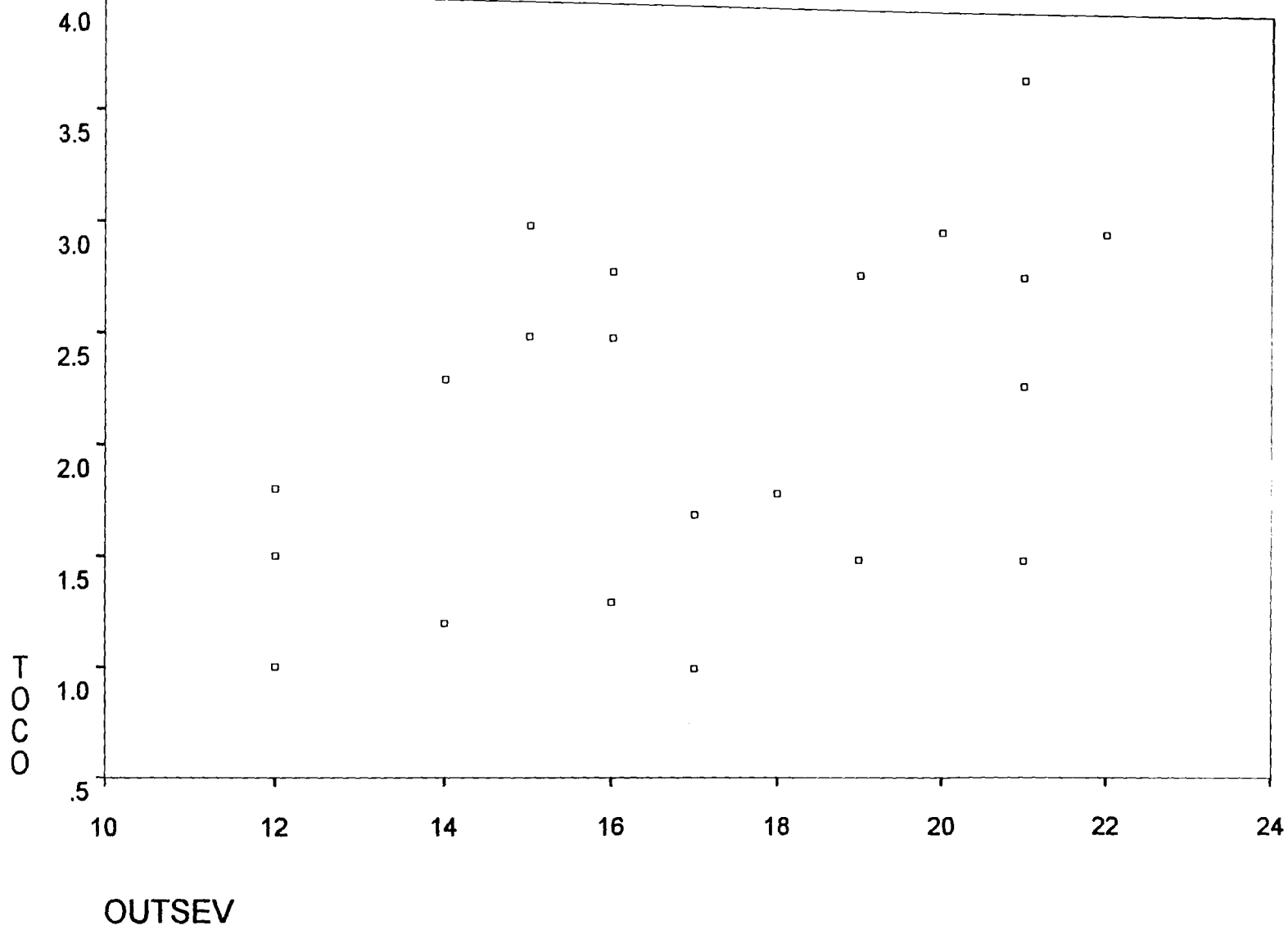
Subjective Severity with Illness Identity

Group 2



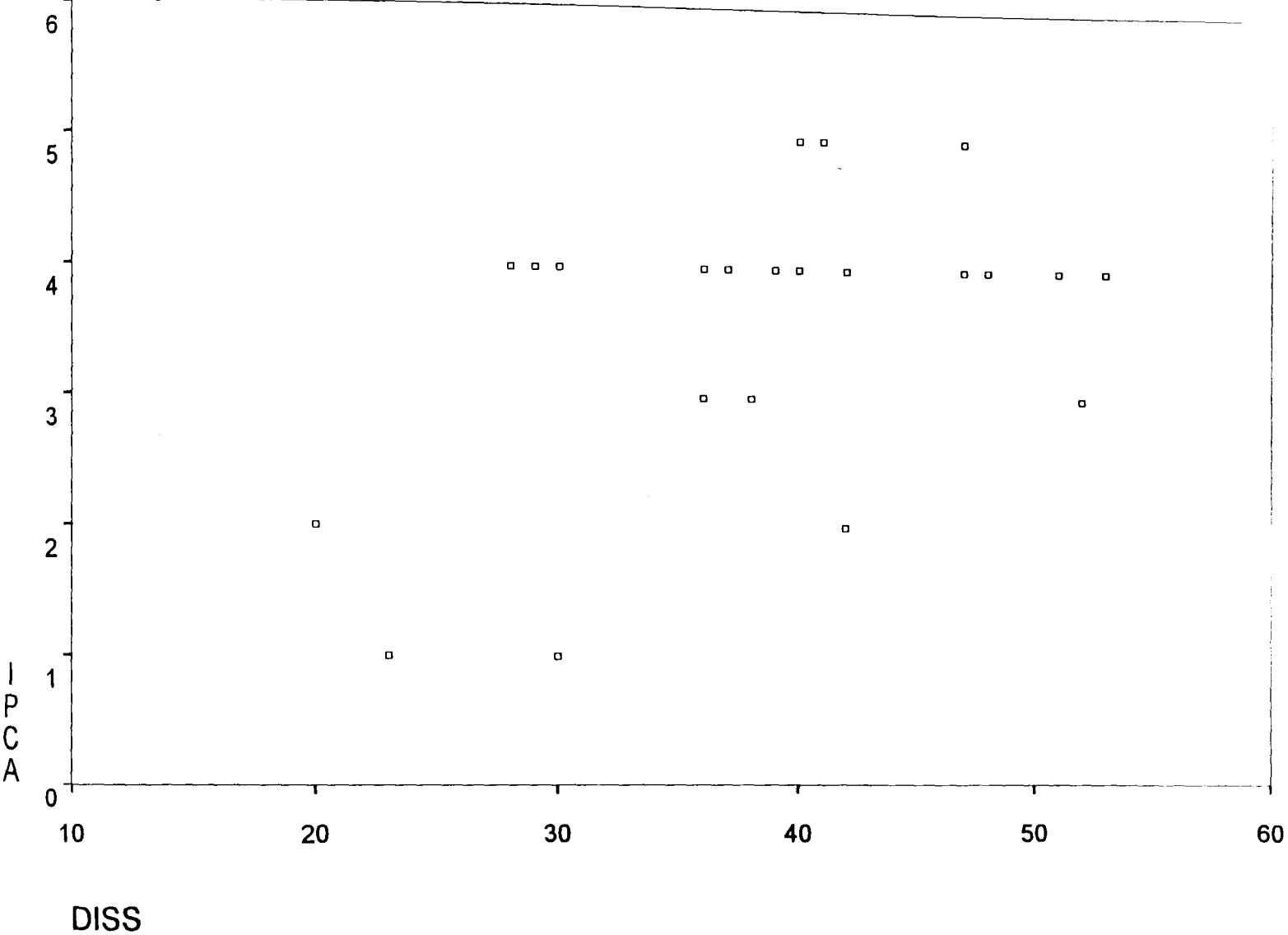
Subjective Severity with Consequences

Group 2



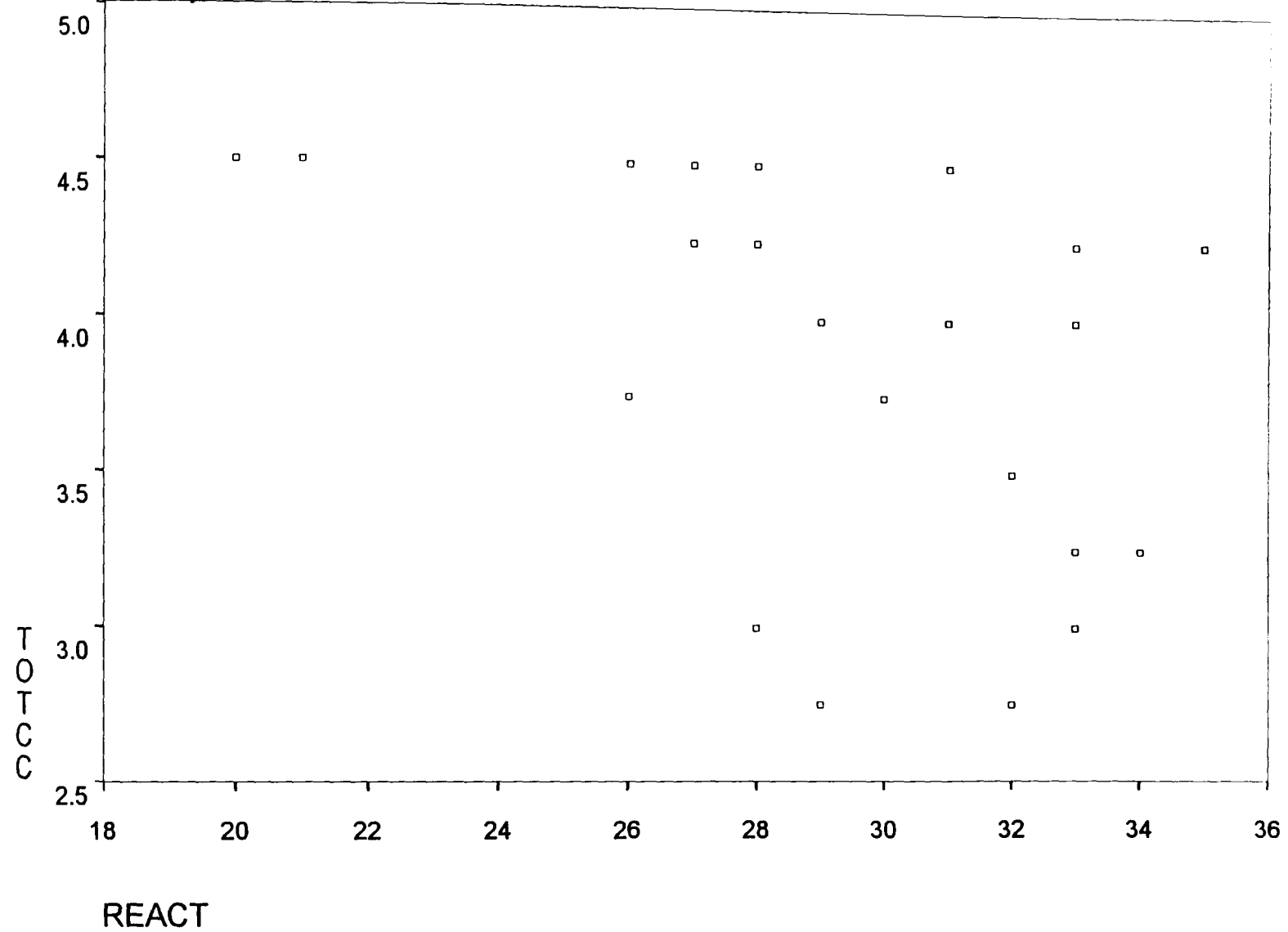
Subjective Distress with Pollution

Group 2



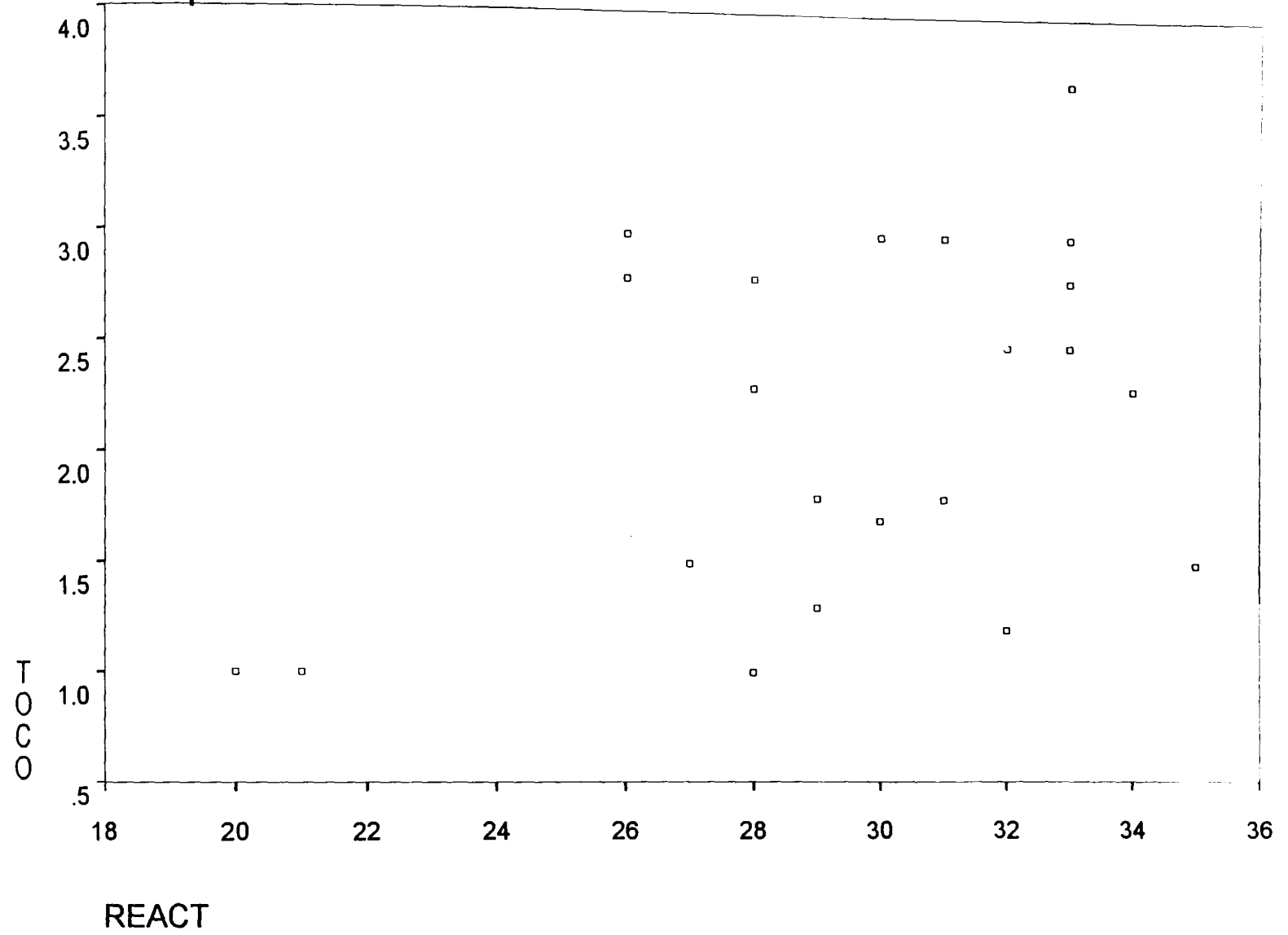
Reactivity with Control/Cure

Group 2



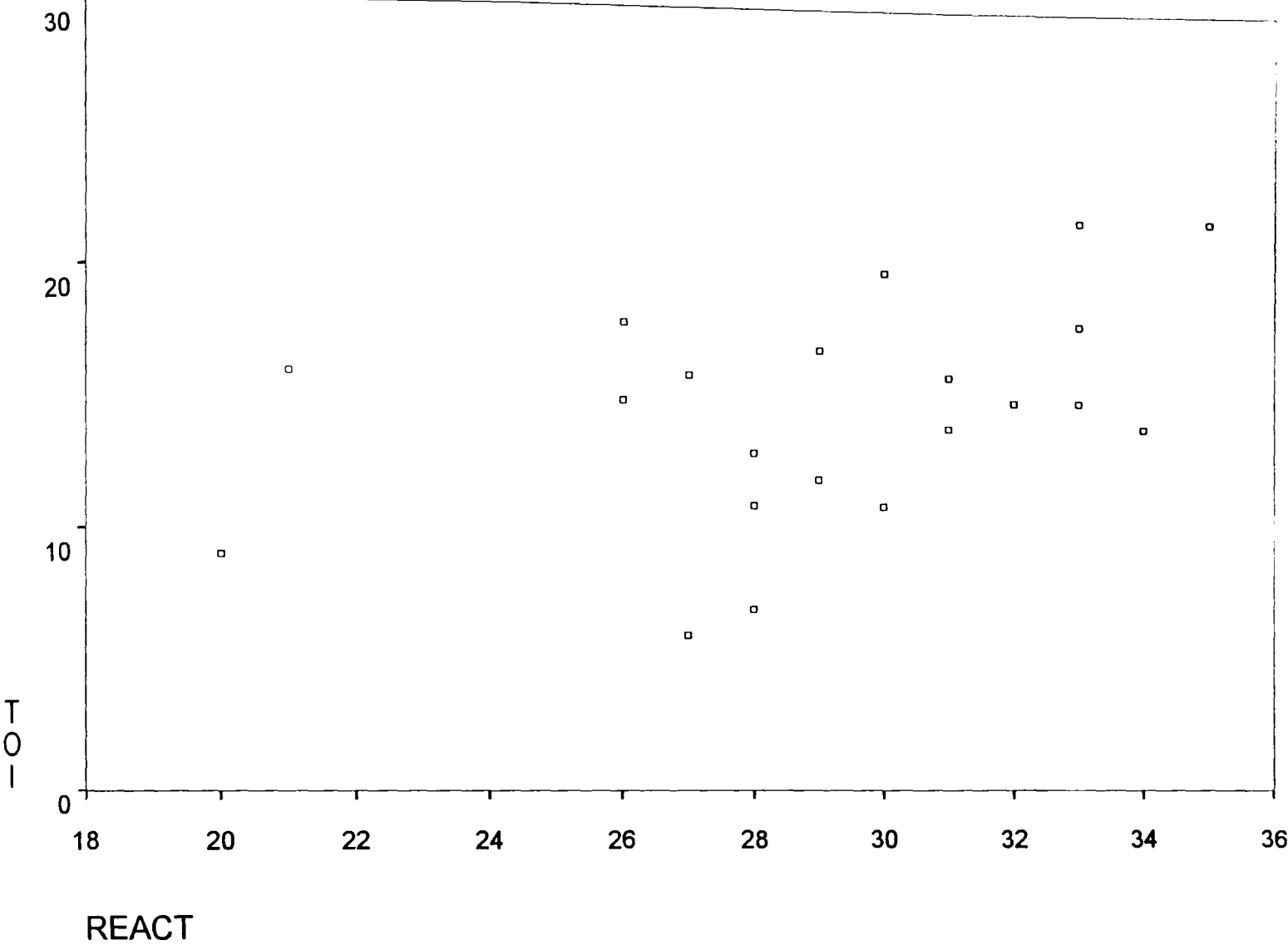
Reactivity with Consequences

Group 2

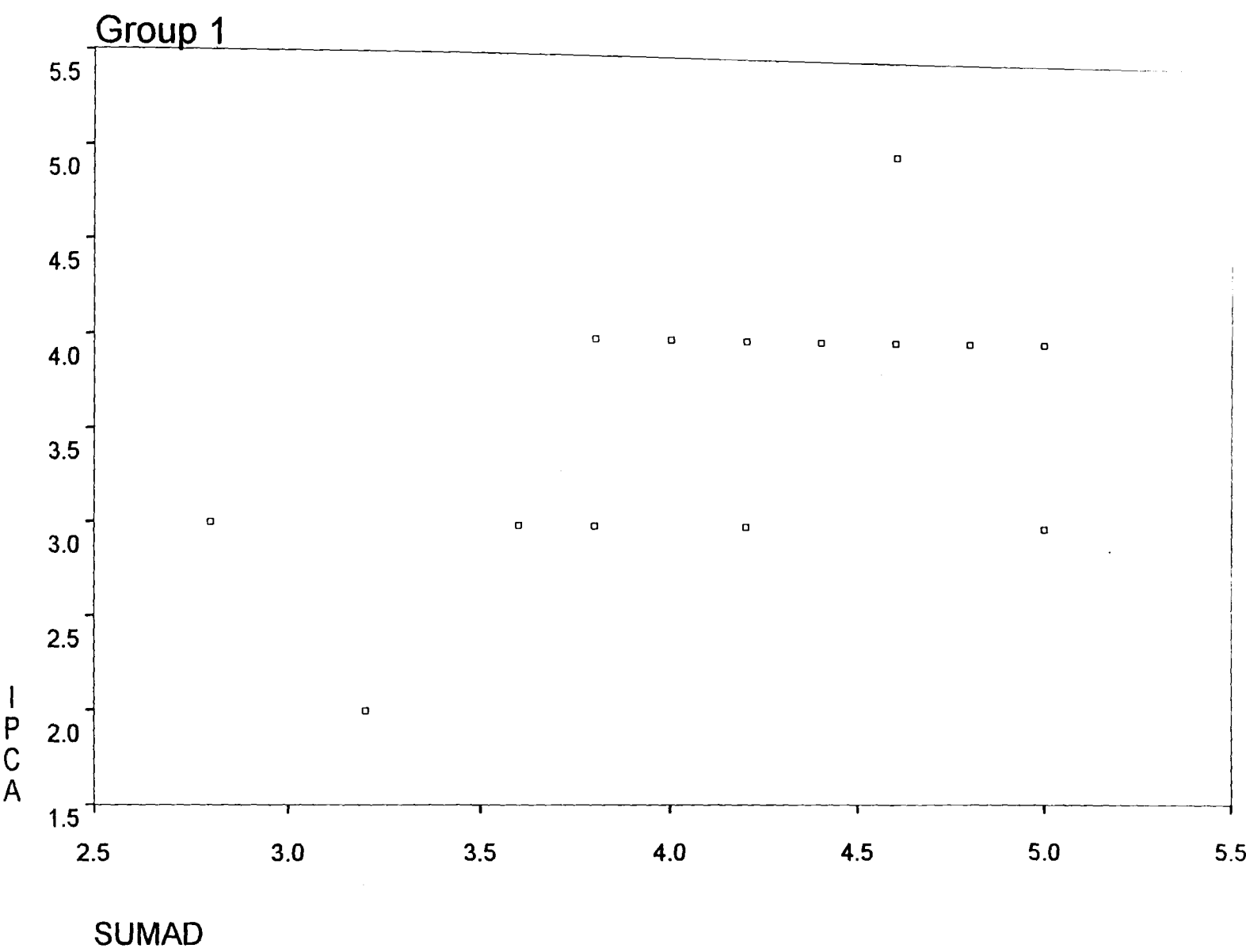


Reactivity with Illness Identity

Group 2

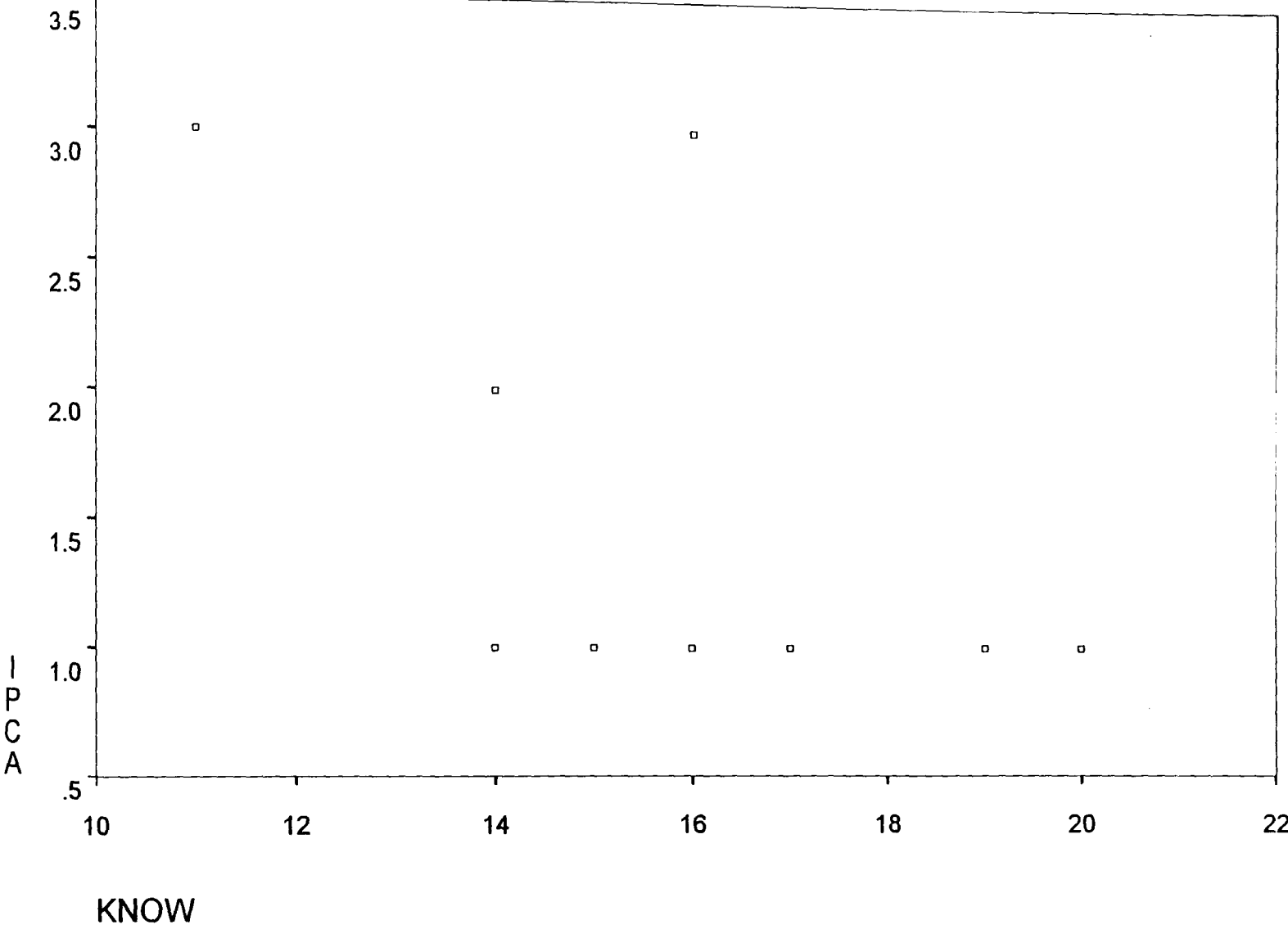


Adherence with Pollution



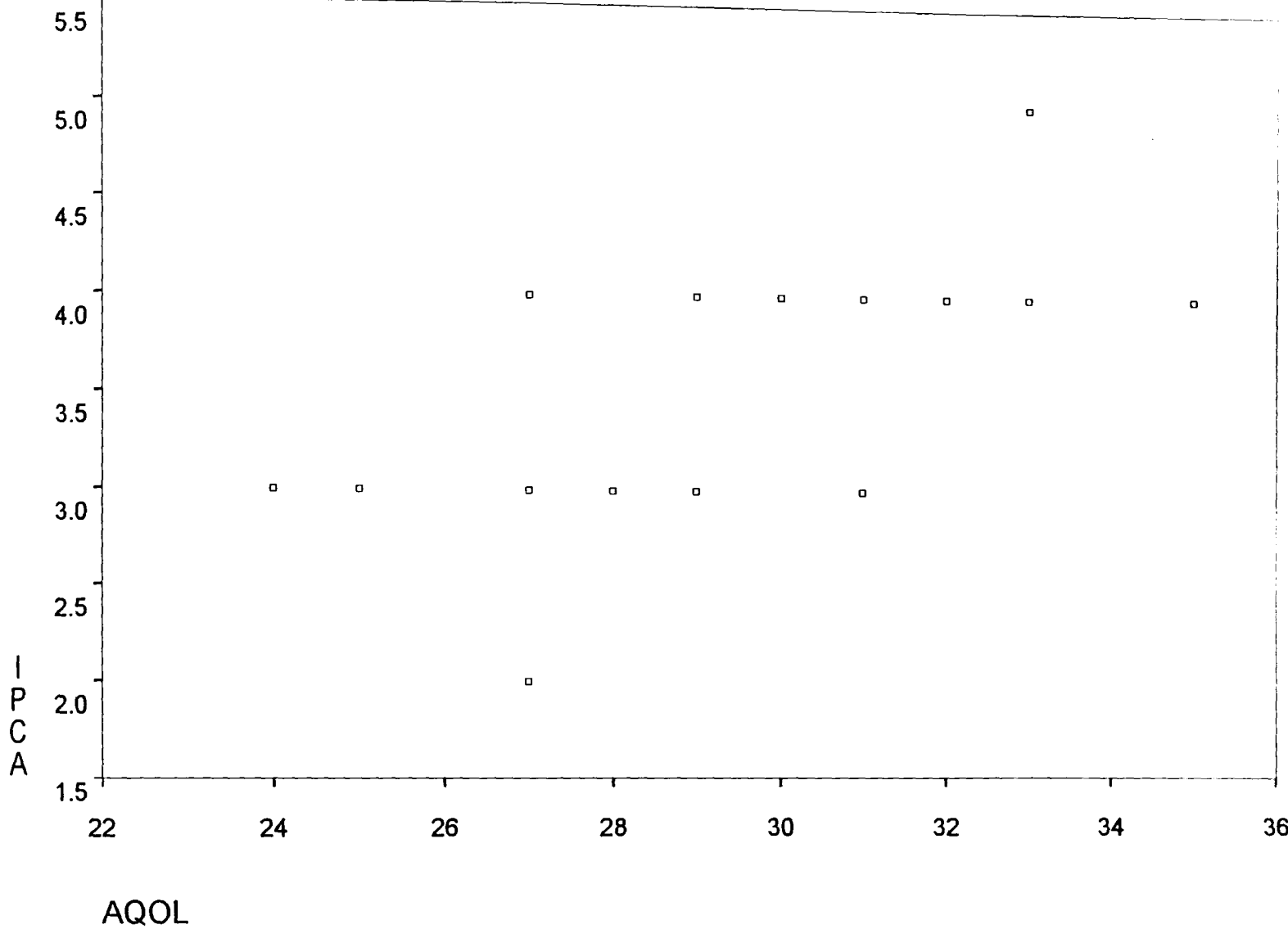
Knowledge with Emotional Causes

Group 1



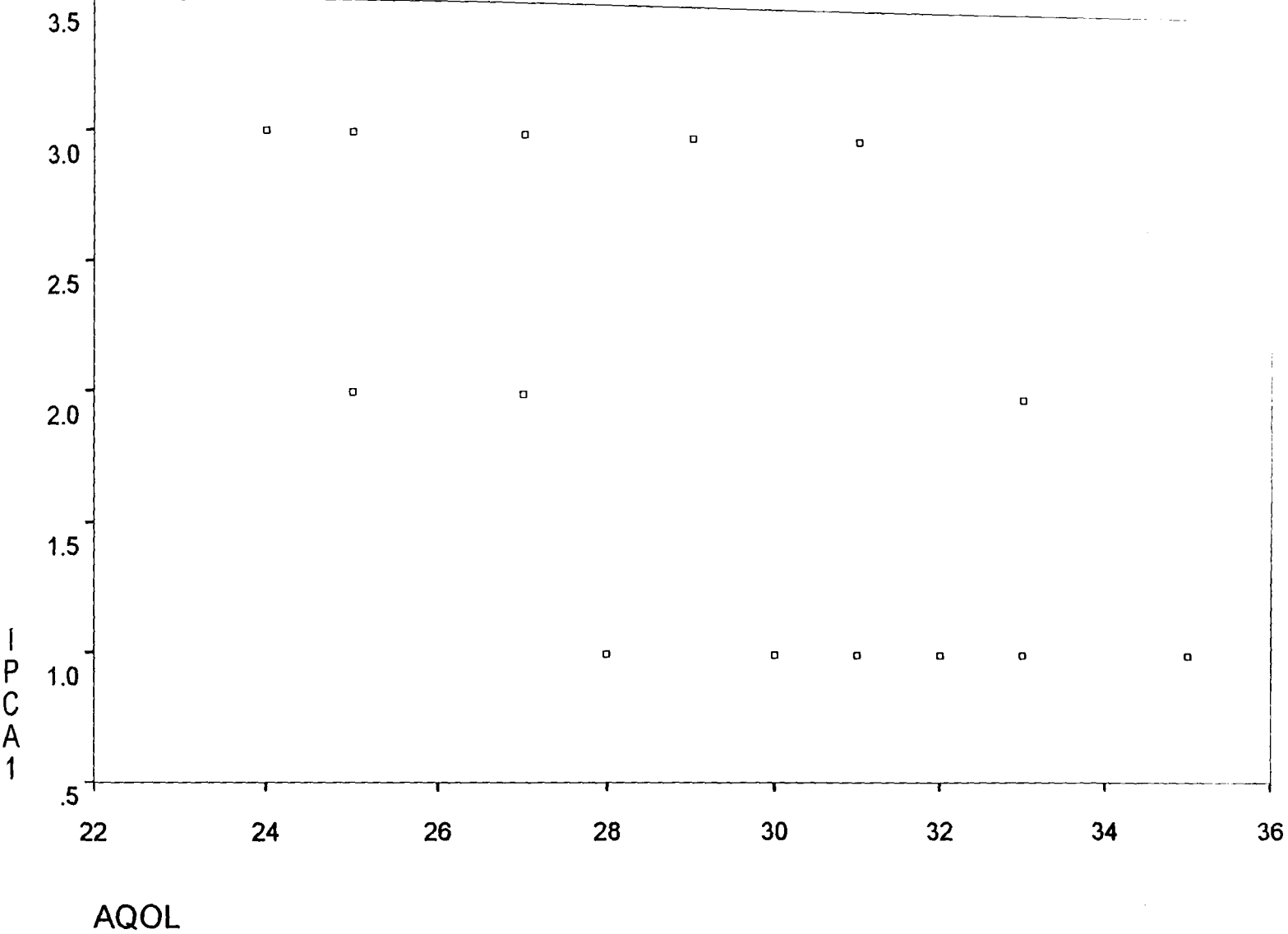
Active Quality of Life With Pollution

Group 1



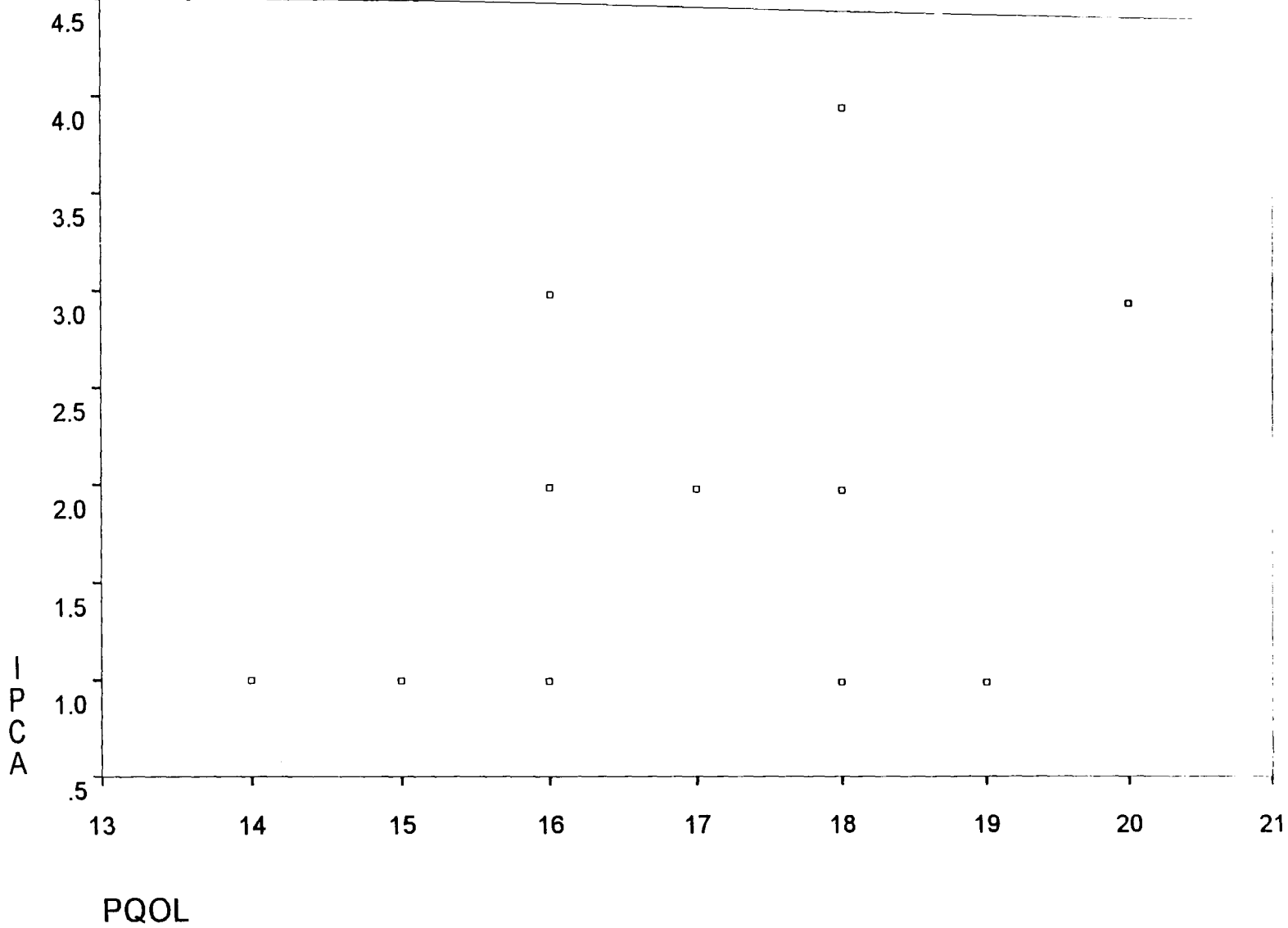
Active Quality of Life with Own behaviour

Group 1



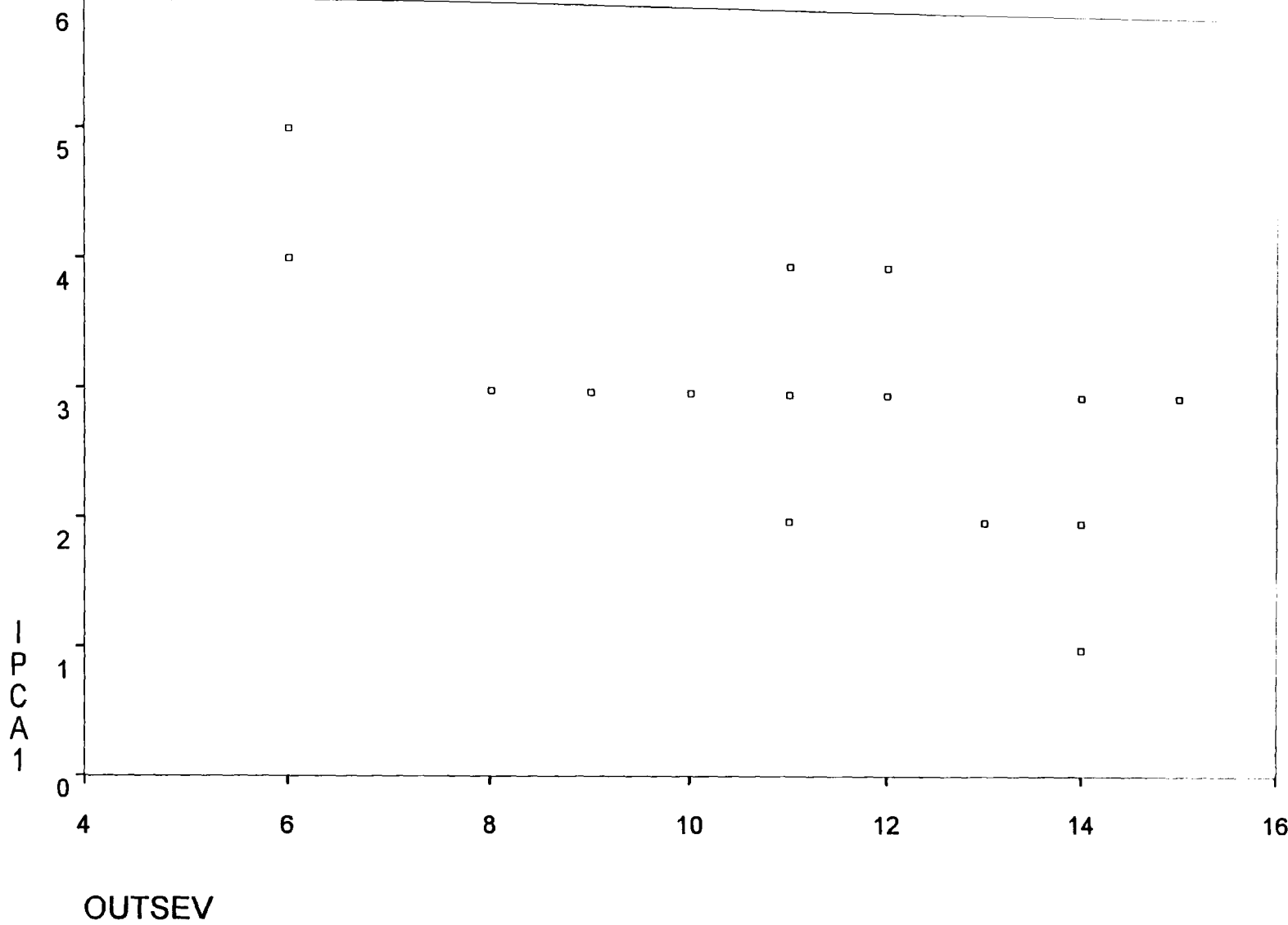
Passive Quality of Life with Stress/Worry

Group 1



Subjective Severity with Germ/Virus

Group 1



APPENDIX 15
DECLARATION

DECLARATION

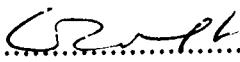
This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed  (Candidate)

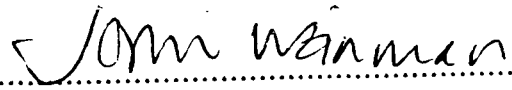
Date 19/7/96

STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed  (Candidate)

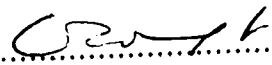
Date 19/7/96

Signed  (Supervisor)

Date 19/7/96

STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and summary to be made available to outside organisations.

Signed  (Candidate)

Date 17/7/96